

THOUGHTS ON FIRE:
THE USE OF METAPHORS IN EPILEPSY NARRATIVES

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ABSTRACT

Epilepsy has a long history of social, cultural, and historical interpretations and representations. Individuals diagnosed with this condition must often learn how to interpret and communicate new experiences after epilepsy disrupts their previously held concepts of identity and control. Both the physical experiences related to epilepsy, particularly seizures, as well as the social experiences related to epilepsy, particularly the impact on one's social identity, can be difficult to communicate using conventional language. As such, individuals with epilepsy might resort to metaphor to convey complex experiences using more accessible language. Previous research has identified a significant role for metaphor use in illness narratives (Kleinman, 1988), as well as in epileptic seizure conceptualizations (Plug et al., 2009), suggesting that metaphor use can be useful in communicating and understanding epilepsy experiences as conveyed through narrative. In order to explore metaphor use in epilepsy narratives, five participants with epilepsy were invited to share written accounts, as well as oral narratives that were then transcribed. These written and oral narratives were analyzed employing structural and thematic narrative analysis, as informed primarily by Riessman (2008) and Charon (2006). Participants' use of metaphor was as diverse as the participants themselves; the interpretations unearthed a wide range of conceptualizations of epilepsy, shedding light on shame, invisibility, physical struggles, and perceived stigma, with narratives and metaphors that primarily communicated attempts to gain control. A focus on perceived control has commonly been identified in epilepsy literature and has increasingly become a target in psychological treatment approaches for epilepsy. By attending to the metaphor and narrative strategies used to convey epilepsy experiences, including strategies used to convey experiences of control, we can highlight the utility and importance of healthy communication strategies when providing support to those with epilepsy.

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CHAPTER ONE

Introduction

If epilepsy does have a face, it looks something like mine: a bit lopsided, scars on the eyebrow and forehead and chin. Leftovers of bruises and black eyes. Inside the mouth: scars and holes where chunks have been bitten out. Teeth missing, gums cut. And the eyes: that buzz. That fire just behind the eyes- it's like a telephone ringing, waiting for someone to pick it up. That person, that thing I never get to see. The shadowy figures. I just feel their hands there, their fingers sliding into my skull, and then there's the dead tone (Robinson, 2006, p. 239).

Author Ray Robinson's (2006) depiction of life with epilepsy presents a frightening and confusing identity, existing as an individual with a condition or "thing I never get to see." This depiction is one of many powerful attempts to communicate the experiences and identities associated with epilepsy, an often challenging task that I sought to better understand through the current study. As described, one of the defining difficulties in living with epilepsy is the fact that during a seizure the individual is often not in control of her or his own body, possibly including her or his cognitive function and level of consciousness. This can lead to confusion, fear, and even shame as individuals attempt to describe personal events and actions for which they themselves are not necessarily consciously present. The experiences associated with epilepsy include both visible elements — for example, seizures, behavioural changes, and injuries — as well as less visible elements — such as perceived rejection from society members who do not necessarily experience or understand epilepsy (Jacoby, Gorry, Gamble, & Baker, 2004).

Individuals must often rely on others to assist them not only with regard to their physical needs,

but also to help explain and co-construct their epilepsy-related experiences. Not surprisingly, those with epilepsy often struggle to give voice to their experience as they attempt to tell their stories, often resorting to imagery — particularly metaphors — to provide an accessible expression of their experiences (Monzoni & Reuber, 2009). Those helping them to make sense of epilepsy-related events often resort to such strategies as well. Both those with epilepsy and their supporters may rely on labels and metaphors, often derived from biomedical or historically-based terminology, in an attempt to facilitate a sense of meaning. Thus, language is crucial in trying to make sense of and understand living with epilepsy.

In medical terms, epilepsy is identified as a “chronic neurological condition characterized by spontaneous seizures, ranging in severity from a lapse in concentration to unconsciousness” (Gilmour, Ramage-Morin, & Wong, 2016, p. 24), which impacts about 0.6% of the Canadian population and about 50 million people worldwide (Fisher, van Emde Boas, Blume, Elger & Genton, 2005; Gilmour et al., 2016; Téllez-Zenteno, Pondal-Sordo, Matijevic & Wiebe, 2004). This reported prevalence is believed to be an underestimate, as many people are reluctant to seek treatment due to their difficulty conceptualizing and communicating their illness experiences (Jacoby, Baker, Steen, Potts, & Chadwick, 1996; Snape, 2015). For those who are assigned the medical label of “epilepsy,” the experience of seizures and other epilepsy-related events (e.g., diagnosis, treatment, psychosocial outcomes, etc.) can lead to confusion, vulnerability, and disruption to individuals’ everyday lives. Epilepsy has been referred to as an invisible condition that, as with other invisible illnesses, is rarely acknowledged unless a visible symptom, a seizure, occurs (Charmaz, 2000). Many individuals with epilepsy may actually desire this invisibility due to identified feelings of fear or shame that they may associate with their condition (Jacoby et al., 1996; Rätty, Larsson, Starrin, & Larsson, 2009). For those diagnosed with epilepsy, the perceived stigma of their illness identity and the psychosocial consequences of this identity often pose a

greater burden to the individual than the seizures themselves (Scambler & Hopkins, 1990; Jacoby, Snape, & Baker, 2005). Bishop and Allen (2003) have stated that,

... because it is at once a medical diagnosis, a social label, and, to some extent, a part of the personal identity, epilepsy, perhaps more than any other disorder, is associated with profound deleterious psychological and sociological consequences that are not directly related to the actual disease process (p. 227).

The impact of epilepsy and its diagnosis as a “social label” has received attention in the fields of sociology and medical anthropology, with a main focus on the social stigma that can accompany diagnosis with epilepsy (Schneider & Conrad, 1983; Good & Del Vecchio Good, 1994; Kleinman et al., 1995). An important example of such a label is the rejection of the term “epileptic,” seen as stigmatizing and as demoting the person in favour of the medical condition (Scambler, 1989), which was replaced with the term “people with epilepsy” (PWE) in many research and clinical forums since the late 1990s (Jacoby et al., 1997). Interestingly, this terminology is not used consistently and has itself been challenged as promoting stigma, with the argument that it can again be perceived as demoting the identity of those with epilepsy as an abbreviated scientific topic rather than as human beings (Hatcher, 2014; Jacoby, 2014; Reuber, 2014). This is but one example of how the lived experience of an epilepsy diagnosis can impact personal identity, with repercussions for illness conceptualization, psychosocial adjustment, and healthy coping, as studied in the field of psychology.

Only a few studies have focused on communication, specifically metaphor use, in epilepsy narratives that contribute to concepts of illness and personal identities (Bishop & Allen, 2003; Nijhof, 1998, Rätty et al., 2009). The field of narrative medicine has drawn more attention to patients’ narratives and unique forms of communication as necessary elements to consider in medical diagnosis and treatment processes (Charon, 2006; Greenhalgh, 1999; Morris, 2008).

Greenhalgh, a practicing physician and academic in interdisciplinary health sciences, is a strong proponent of the narrative medicine approach. Of narrative medicine she states that, “it is only within such an interpretive paradigm that a clinician can meaningfully draw on all aspects of evidence — his or her own case based experience, the patient’s individual and cultural perspectives, and the results of rigorous clinical research trials and observational studies — to reach an integrated clinical judgment” (Greenhalgh, 1999; p. 325). My interest here is to focus on the communication of individuals with epilepsy as impacted by their “individual and cultural perspectives,” including interactions with the medical community. In this study, I sought to gain a clearer understanding of how people with epilepsy use linguistic resources, specifically metaphor, to make meaning of their epilepsy-related experiences. Furthermore, I attempted to identify the role that metaphors and narrative styles can play in the conceptualization of epilepsy identities.

A review that I conducted of published autobiographies and biographies indicated that personal stories of life with epilepsy are rich in metaphor use (see Appendix A: Published Narratives). In the academic literature, seizure-specific metaphor use has recently been identified as a diagnostically relevant way to distinguish the different types of seizures experienced (e.g., Schwabe, Reuber, Schöndienst, & Gülich, 2008; Plug, Sharrack, & Reuber, 2009). The current study sought to gain insight into not only seizure-specific metaphors, but to metaphors used in reference to all epilepsy-related experiences (e.g., seizures, diagnosis, treatment, psychosocial factors, etc.). As a few epilepsy narrative studies have identified heterogeneity in individuals’ epilepsy conceptualizations (Faircloth, 1998; Nijhof, 1998; Rätty et al., 2009), I expected that a diversity of metaphors would be used, and indeed found just that. I paid particular attention to the possible sources of the metaphors, such as dominant biomedical and historical discourses, as well as those that appeared more idiosyncratic. I based my investigation on the understanding that

metaphor, as a linguistic resource, enables individuals to make sense of their epilepsy by describing unfamiliar experiences in terms that are more familiar to them. Thus, the first questions guiding the research were: *What metaphors do individuals use to communicate and make sense of their epilepsy experiences, and what role do these metaphors play? Are these metaphors prevalent in existing discourses surrounding epilepsy (e.g., biomedical terminology, socio-historical beliefs) or are they more often idiosyncratic?*

A second goal of the study was to gain an understanding of the presence (or lack thereof) and use of metaphors in illness and identity constructions after diagnosis with epilepsy. I did so by focusing on the way in which metaphors in the illness narratives were used to convey individuals' experiences of epilepsy and their identities. Preliminary observations of epilepsy autobiographies and biographies suggested that people with epilepsy are eager to make sense of their experiences through storytelling but can be hesitant to identify themselves as having epilepsy. While illness narratives are a valuable strategy used to make meaning of new identities after a diagnosis, people with epilepsy have generally been found to perform a more gradual disclosure of their diagnosis as they re-negotiate their identities (Kleinman, 1988; Kiliñç & Campbell, 2009). Together, these findings indicate that people with epilepsy are eager to understand and narrate their experiences but that they do not tend to do so until they have achieved a significant level of perceived control over their illness, including their illness identities (Velissaris, Wilson, Salis, et al., 2007). This perceived control often results from both medical management of symptoms, as well as psychosocial management of identity through storytelling (Frank, 2010), perhaps drawing attention to the enormous vulnerability of a life where, in a second, a sudden seizure can annihilate any sense of control. I therefore asked a second set of questions: *How do people with epilepsy use storytelling to make sense of their*

experiences and their identities after diagnosis? How is metaphor used in the (re-) construction of these stories?

In order to contribute to this body of research, I carried out a qualitative study that explored the linguistic strategies of metaphor use and storytelling by people with epilepsy. The focus was on how these strategies are used to conceptualize and to communicate epilepsy-related experiences, and how these strategies ultimately come to play a role in identity re-construction. The narratives that I collected help to provide insight into the diverse ways in which people with epilepsy conceptualize their experiences and their identities. The narratives are also intended to provide awareness of how medical and socio-historical concepts of epilepsy, as communicated through metaphor and common medical narratives, impact people with epilepsy as they make meaning of their experiences and renegotiate their identities. Ultimately, I sought to further understand how diverse metaphors play a role in individuals' representations of their epilepsy experiences and personal identities, including how they may be useful and/or problematic in different ways to people with epilepsy and the people who care for them.

I developed my study objectives through a review of the literature surrounding the terminology and concepts to be examined, first considering core concepts of metaphor, the role of metaphor within narrative analysis, then within the field of chronic illness and health research, and finally narrowed to the role that metaphor and narratives have played in epilepsy research specifically. As my findings evolved, I returned to the literature frequently to elaborate and update research sources in those areas of study that became more pertinent to my outcomes. Thus, in Chapter 2, I provide a *Literature Review* of those sources that informed my analysis, both in determining my initial research questions, as well as those that informed my final analyses. I revisit these sources and others throughout the *Analysis* chapters, as different sources apply depending on the way in which each narrative directed the focus on my analysis. This

dialogue, between myself, the literature, and the narratives, illustrates the co-construction of meaning that took place.

In Chapter 3, I review my analytic approach to the study including a brief overview of the metaphor analysis and narrative analytic approach that I adopted, including the ontological and epistemological stances that these involved. As will be discussed, my analysis leaned heavily on the narrative medicine approach to understanding illness experiences, and neurological illness more specifically (Alcauskas & Charon, 2008; Charon, 2006). I found that the narrative medicine approach aligned well with my training and experience in the clinical domain, in which I often review biomedical files related to individuals' disease states and must consider these as one form of narrative that may provide context for the individuals' narrativized illness experiences (Greenhalgh, 1999). Narrative medicine helped me to remain mindful of the approach to language and narratives from the perspective of the biomedical model, which tends to focus on narratives in the form of diagnostic and treatment trajectories; it encourages clinicians to be mindful of the multiple narrative interpretations and contributions that constitute illness experiences (Charon, 2006). Charon's (2006) approach provided me with tools to consider what assumptions I was bringing to the conversations I had with participants, including key assumptions about narrative approaches and terminology that could be considered common in everyday dialogue, as well as those that may have evolved from patient-practitioner interactions. This chapter also reviews my recruitment approaches with participants and those sources of data that were used within the analysis.

The main body of my study consists of *Analysis* chapters (Chapters 4 to 8) in which I reviewed the narratives of five participants in the form of case studies. Each chapter begins with a brief introduction to the participant, followed by a re-construction of their narrative based on a submitted written narrative, an oral narrative co-constructed between each participant and myself,

informal communication collected throughout the recruitment and follow-up stages, and field notes involving my reflections throughout my interactions with the participants and their narratives. My first interest was in attempting to understand trends within each participant's individual narrative; this included topics that they tended to focus on or target in their language use, as well as themes or specific metaphors that seemed recurrent or central to their narratives. I also had interest in the similarities and differences between participants based on their language use and narratives, and this was at least in part impacted by demographics such as gender (3 women, 2 men), relationship status (2 married, 2 divorced, 1 single), parental status (3 are parents), age at time of interviews (38 to 64), and aspects of their illness (e.g., age of seizure onset, seizure typology, treatment, etc.). The *Analysis* chapters are presented as narrative reconstructions that were developed through the use of thematic and structural narrative analysis (e.g., Charon, 2000; Riessman, 2008). The primary focus of the analysis was on language, specifically metaphor, in which I considered the target topics (e.g., seizures, treatment, etc.) that metaphor was used to describe, as well as any themes that I perceived in the source of the metaphors used (e.g., electricity, body as a broken machine, etc.). I focused on those metaphors that I interpreted as most salient to each participant, based on the participant's use of the given metaphor(s) and the role that such metaphor(s) held in conceptualizations of her or his larger narrative framework. A common outcome that became apparent as I reviewed all of the narratives was the theme of loss of control, which was introduced in descriptions of participants' first seizures, but which remained a pervasive theme and focus for metaphors and identity conceptualizations. I thus focused on metaphors and overarching themes upon which participants relied to communicate their relationships with loss of control, and with their attempts to regain control within moments of seizure occurrence and often more broadly throughout their daily lives. My final *Analysis* and *Conclusion* chapters provide reflections on my original study

questions and summarize the primary metaphors identified in the five participant narratives, including consideration of how these metaphors relate to past research on epilepsy narratives. I reflect on how these metaphors may provide unique or shared meaning(s) for the participants, as well as others who experience epilepsy, positioning the study as a fruitful opening for others to consider the value of individuals' language as a means to gain a better understanding of illness experiences.

CHAPTER TWO

Literature Review

The following review of the literature serves several purposes. First, I seek to orient the reader to my study by reviewing the key concepts of interest, including: 1) metaphor and its use in illness; 2) concepts of self and identity; and 3) illness narratives and identity construction. Second, an introduction to the history of epilepsy provides a consideration of common socio-historical and biomedical terminologies. Third, I review results from previous studies of epilepsy narratives, observing the way in which past researchers have considered and categorized epilepsy narratives, as well as speculating on the role that metaphor may have played in such narratives. Fourth, a review of research targeting seizure-specific metaphors is reviewed to illustrate how and for what purposes metaphors can serve as a useful tool in understanding patient conceptualizations of epilepsy-related experiences. Finally, a review of autobiographies and biographies is used to consider the role of metaphors in construction of published epilepsy narratives. Given the iterative nature of my research, this final section has been expanded over the course of my analysis, as researchers continue to publish and as my findings revealed a crucial connection to the central theme of control in seizure- and epilepsy-related metaphor. Mostly, this literature review highlights that despite the prevalence of metaphor in epilepsy narratives, there remains a gap in our understanding of the roles that metaphors play — sometimes therapeutic and/or problematic — in conceptualization of epilepsy experiences and identities.

2.1 Metaphor Use and Illness

In this section I will discuss select definitions applied to the concept of metaphor. I will then address the prominent role that metaphors play in both cultural discourse of illness and illness narratives. Finally, I will outline the definition of metaphor that I intend to use in my analysis.

2.1.1 Origins of metaphor. The term “metaphor” originally derives from the Greek “*metaphero*” meaning “to carry over” or “to transfer” (Harmon & Holman, 2009). The concept of metaphor was first identified by Aristotle in *Poetics*, where he provided four types of metaphor as: “the application of a strange term either transferred from the genus and applied to the species or from the species and applied to the genus, or from one species to another or else by analogy” (Grube, 1958, p. 44). According to Grube (1958), this Aristotelian definition is much broader than that used in modern-day language, as it describes the substitution of one word for another as a “decorative” strategy so long as the term still makes literal sense. This focus is expanded upon in Aristotle’s *Rhetoric* where metaphor use is said to make sense only when there are some clear similarities in the two terms. When the substitution of one word with another occurs, the focus on similarities in seemingly dissimilar things is supported by Aristotle’s statement that: “The right use of metaphor... comes from the ability to observe similarities in things” (Hammond, 2001, p. 48). For the purpose of this study, my interest in “metaphor” is that one described in Aristotle’s reference above: an analogy, otherwise identified as the cognitive process involving the transfer of a word and by association its meaning from one context to another (Grube, 1958; Harmon & Holman, 2009).

2.1.2 Metaphor theory. In *Metaphors We Live By*, Lakoff and Johnson’s (1980) Conceptual Metaphor Theory (CMT) is in line with their cognitive concept that parallels

analogical models, identifying metaphor as a word or phrase that can be understood beyond its literal meaning in the context in which it is used. The phrase is drawn from the “source,” an experience with which individuals have prior sensory or cultural experience, and is transferred to a “target,” which is more abstract and perhaps harder to explain, such as experiences with illness (Lakoff & Johnson, 1980; Johnson, 1997).¹ In regards to the “source” as the experiential component, Lakoff and Johnson (1980) endorse the belief that primary conceptual metaphors are often a product of embodied experiences (both physical and/or social) that are made meaningful through reinforcement. For the purpose of my study, I found it helpful to consider how Ritchie (2006) builds on Lakoff and Johnson’s CMT in his “Context-Limited Simulation Theory.” Ritchie (2006) helped to narrow my definition of “metaphor” with his emphasis on how metaphors are communicated in the context of a conversation. He proposed that individuals involved in a conversation are only likely to interpret a metaphor in the same way if there exists common cognitive activation of knowledge, images, and emotions (Ritchie, 2004, 2006). As such, the metaphors that an individual uses in a given context might depend upon his or her perception of the other’s cognitive environment, including the set of metaphors that he or she can cognitively access (Ritchie, 2006). Furthermore, there remain individual interpretations of the figurative language used in conversations, with the implication that the speaker’s intended meaning of a given metaphor may not be accessed and understood in the same way by the listener (Ritchie, 2004).

Ritchie’s (2004, 2006) theory has significant implications for individuals trying to communicate any experience. For illustrative purposes, I consider it in the context of a patient-physician conversation in the mutual task of making meaning of illness experiences. For

¹ An example would be the metaphor “cancer is war,” where “war” would be selected from the (familiar) source area and “cancer” would represent the (unfamiliar) experience or target area.

example, patients may use metaphor selectively based on what they perceive physicians will understand (i.e., what they may perceive as physicians' cognitive environments). The only way in which physicians – according to Ritchie – are said to truly understand the conceptual metaphor used is if they do indeed share the same meanings as their patients. Ultimately, this interaction is limited both by the patients' selections of what they perceive to be accessible metaphors, as well as physicians' interpretations and assumptions that they have accessed the appropriate meanings. For example, patients may describe feeling “cloudy” or “in a fog,” which for them may conceptualize feelings of confusion, loss of awareness, or loss of control during a seizure, but which in the biomedical realm of physicians may be conceptualized as altered cognition or sedative effects associated with seizures and anticonvulsants. Ritchie (2004) emphasizes that unrecognized differences in background knowledge, beliefs, and cultural differences can significantly interfere with communication attempts in general, particularly when metaphor is involved. Deignan (2003) has also suggested differences in metaphor use and comprehension based on culture.

Kirmayer (2000) further addresses a greater role for culture by defining metaphor as: “intermediate ground between embodied experience and overarching narrative structure of plots, myths and ideologies” (p. 156). This may be congruent with Lakoff and Johnson's “complex metaphor” in which the metaphor may be grounded in a vicarious experience mediated by personal, historical, fictional or mythical narratives (Kirmayer, 2004; Ritchie, 2006). Understood in this way, metaphors are “tools for working with experience” (Kirmayer, 1992, p. 335) and can be seen as serving two main purposes: 1) to construct and conceptualize new meanings; and 2) to communicate meaning to others through social interaction (Kirmayer, 1992). These two main purposes are constrained by socially-accepted metaphors and narratives, unless it is acknowledged that new meanings can emerge as a social construction (Kirmayer, 2000). While

Lakoff and Johnson brought attention to the embodied sensory and socio-cultural experiences that serve as the origins of metaphors, Kirmayer and Ritchie emphasize that every metaphor encountered is a product not only of individuals' constantly evolving experiences and expressions with a spotlight on social construction, where individuals may be limited by those concepts to which they are exposed in expression and interpretation of metaphor.

2.1.3 Metaphor theory and illness. Biomedical models often treat metaphors as objective, literal information when used in patient-physician discourse (Charon, 2006; Kirmayer, 1993). It is important to be aware of “dead metaphors” that are thought to have lost their original literal meaning through extensive popular usage, for example, “living life on the edge” (Harmon & Holman, 2009; Healey, 2009). Dead metaphors have a conceptual meaning that differs from the original meaning of the word or phrase, and therefore may be understood without needing to know their original connotation (Harmon & Holman, 2009). Multiple authors helpfully emphasize that dead metaphors should still be considered as “creative” metaphors that may be interpreted figuratively rather than literally, making awareness of metaphor use an important exercise (Donoghue, 2014; Kirmayer, 2000). Those in the biomedical forum indicate that successful understanding can only take place if one maintains awareness that all metaphors used in the patient-physician interaction are socially constructed based on both unique bodily experiences and social interactions (Gergen, 2015; Kirmayer, 1993; Zaner, 1988). As such, physicians may apply diagnostic labels and descriptions as something they intend as literal information; however, these labels and descriptions may directly impact the patients' meaning-making of their illness experiences depending on how this information is interpreted (Gergen, 2015; Zaner, 1993). For example, a physician may inform people with epilepsy that their seizures are a consequence of “electrical disturbances,” a term that may be considered a dead metaphor used in reference to brain activity given its prevalence in biomedical terminology. In one

narrative, however, the narrator demonstrates a misinterpretation of the physician's communication, describing fear that she might electrocute others given the "electrical activity" involved in her seizures (Robinson, 2006). Conversely, patients' descriptions of their symptoms may involve idiosyncratic metaphors that physicians may mistake as literal information, or may dismiss if it is not seen as relevant to the objective information needed for diagnosis (Gergen, 2015; Kirmayer, 2004). For example, one narrator described "feeling ugly" which might be addressed as a solely psychosocial concern but, as she explained to the reader, she used this to refer to the distorted perceptions of her physical self that she experienced as part of her seizures (Slater, 2000). Kleinman (1988) further supports the importance of carefully attending to these potential confusions in communication in the following statement: "The physician's training encourages the dangerous fallacy of over-literal interpretation of accounts best understood metaphorically" (p. 52).

A final and particularly relevant implication of Kirmayer's (2004) discussion of metaphor in illness is his discussion of healing and the associated transformation of personal identity. Kirmayer (2000) observed that culturally valued rationality and control lead patients to learn and use biomedical terminology, contributing to feelings of self-efficacy and control. Nonetheless, patients' perception of power based on learned biomedical terminology may indeed be just a perception, as their interpretations of such language may not be accurate and as they must remain submissive to physicians when undergoing treatment or receiving new information (Kirmayer, 2000). Overall, Kirmayer provides a helpful view of the diverse ways in which individuals engage with linguistic resources, such as metaphor, as they navigate through illness experiences. Let us now consider how this linguistic resource is used in the larger context of the illness narratives.

2.1.4 My definition of metaphor. Having reviewed diverse perspectives on the concept of metaphor and its application in illness narratives, I will now identify the elements that were essential for my analysis. I relied on the origin of metaphor from the basic Conceptual Metaphor Theory in which there exists a familiar source domain (formed from sensory or cultural experience) that lends meaning and is contextualized by transfer to the more abstract target domain (Lakoff & Johnson, 1980). This definition was further informed by Kirmayer's assertion that such metaphors serve the purpose of: 1) conceptualization for oneself; and 2) communication of experience to others. I have paid attention to both of these potential functions in the narratives, with particular interest in contextual elements, that is, when the metaphors are used in reference to particular interactions, as discussed in Ritchie's (2006) focus on conversation-specific and context-specific elaboration. Also of particular interest was how medicalized terms — some of which may be considered dead metaphors and possibly (mis-)taken for their literal meaning — may be used and integrated into concepts of identity (Kirmayer, 2000; Kleinman, 1988). Finally, there exists a role for metaphor in conveying individuals' perceptions of and relationships to their illness (Radley, 1993). This role will be explored in more detail in the section on illness narratives. Before reviewing the use of metaphor in the narrative context, I will first define the concepts of *self* and *identity* that I believe to be impacted by the use of metaphor.

2.2 Self and Identity

Though we may not always be aware of it, the metaphors and narratives that we observe, whether or not they portray illness experiences, are always told by a narrator: a *self*. An early concept of self was proposed as consisting of the thoughts or perceptions that individuals have of their feelings and physical sensations (James 1891/1980; as cited in Gray, 2005). Such a definition leaves open the possibility of a singular self that remains constant over time despite

changing conditions, with the self possessing agency to choose which sensations it focuses on and how it makes sense of these experiences (Gray, 2005). Mead elaborated on the concept of a singular self that is constituted of an “I,” the internal individual experiencing events, and an external “Me” who is interpreting such events through social interaction and discourse (Mead, 1968; as cited in Crossley, 2000a). Mead (1968) identified an “I-self” as equivalent to a biological self that, over the course of human development, becomes socialized and ritualized into a “Me-self” that expresses the feelings of the “I-self” in socially-acceptable ways. These theorists argued for the concept of a singular and continuous self, though the multiple experiences and reactions that such a self may have in different social circumstances lends itself to the possibility of multiple selves, a different self for each different social situation (Gray, 2005).

Bruner (1990) identified a “conceptual self” in which there exists no one “true self” because one’s concept of self is a product of reflection upon experiences and thus is invariably influenced by memory, thought, and language. De Munck (2000) also supports the notion of self as conceptual, constituted as a collection of narratives that people tell themselves and others. Individuals often infer that a single author, a single “true self,” produces this collection of narratives but there are actually many different narratives that can be told about the same event, and many different selves that may be presenting them (Dennett, 1991; as cited in de Munck, 2000). Many researchers contend that multiple selves can exist given the multitude of ways in which individuals may experience and interpret the same event (Bruner, 1990; Crossley, 2000a; de Munck, 2000; Gray, 2005; Sparkes & Smith, 2008). A helpful notion in the context of this study is that the concept of self is dialogue-dependent in that all narratives expressed are directed at an audience, whether it is oneself or a general audience, and therefore different selves may be presented depending on the audience (Bruner, 1990). The self is identified as a social construct in

that: “The self expresses itself and is apprehended by others with the linguistic/communicative resources at hand” (de Munck, 2000, p. 46). Gergen (1991) helpfully emphasizes the continuous construction and re-construction of selves as individuals participate in different discourses and are exposed to different linguistic resources. Ewing (1990; as cited in de Munck) also advocates for self-representations that are dependent on language, particularly metaphor and narratives, and such self-representations are proposed to change as one changes contexts. This body of research leads to a conceptualization of self and identity that will be used in addressing this analysis. Self is defined as: 1) a concept rather than a singular “true self;” 2) constructed through multiple narratives and; 3) involving continuous changes due to changes in context and language use. Let us now consider how the use of both metaphor and narrative play a central role in the conceptual development of self and identity.

2.2.1 Locating self in illness narratives. In the current study I focused on both oral and written accounts of events provided by participants with epilepsy, that is, oral and written narratives. Illness narratives, sometimes also labeled as *pathographies*, refer to narratives told by individuals about their illness and its effect on their lives (Kleinman, 1988). Such narratives may help individuals to conceptualize and articulate illness experiences and events. Narratives are often told chronologically and, indeed, the participants I spoke to tended to provide narratives that focused on the linear medical trajectory; however, some participants were more chaotic in conveying comprehensive narratives of all illness-related events. Denzin and Lincoln (2000) identify metaphor as a literary device that serves to link separate experiences or “parts” of a narrative into a functional and coherent whole. Seen in this light, metaphors can be paralleled with the concept of “narrative linkages” that serve to bring together a complex group of narrative pieces and, through their juxtaposition, create a coherent narrative (Denzin & Lincoln, 2000). Bruner (1990) helpfully highlights that most illness narratives do not gain coherence from a

single root metaphor as Lakoff and Johnson (1980) might propose, but rather gain coherence through diverse metaphors used to connect a sequence of experiences.

Leventhal and colleagues emphasize that theories of illness, conceptualized through illness representations such as metaphor and imagery, are based on both bodily experience and external information (Leventhal, Leventhal, & Cameron, 2001). These representations usually address one of five aspects of illness experiences: 1) illness identities (e.g., diagnostic labels, symptoms), 2) timelines (e.g., onset, duration), 3) perceived causes (e.g., genetics, physical condition), 4) consequences (e.g., social impact, limitations), or 5) controllability (e.g., possible cure, control). It is important to note the impact of external information on construction of illness representations, as individuals interact with existing labels and constructs to make sense of their experience (Leventhal et al., 2001). Furthermore, it is noteworthy that an illness narrative might well involve several perspectives or representations in constructing identities. To consider these representations in the context of epilepsy narratives, we can turn to Faircloth's research (1998a, 1998b), which emphasizes that though there may be consistent themes present in epilepsy experiences (e.g., initial seizure and epilepsy "discovery," social consequences of the epilepsy label, etc.), the language elements used to connect or express the overarching experiences should be prioritized in interpretation of the individual's experiences. It has also been emphasized that it is the way in which an individual's narrative is communicated (the *how*) rather than the standardized themes (the *what*), which highlights the utility of metaphor in epilepsy narratives (Schwabe et al., 2007; Nijhof, 1998). Thus, the salient features of an individual's narrative may be the metaphors that serve to express experiences beyond the thematic divisions, or the narrative may derive from one central metaphor that individuals use to convey their sense of self and of the experience as a whole.

As the majority of individuals diagnosed with a chronic illness experience a disruption in their sense of identity, narrative re-construction is relied upon to varying degrees in order to integrate personal understanding of the illness with perceived public expectations (Radley, 1994). A commonly-perceived need for individuals to “normalize” includes the ability to account for illness while maintaining existences that meet “normal” functioning in society (Parsons, 1951; Radley, 1994). The central metaphors used by individuals with chronic illness tend to reflect the way in which they respond to illness, identity disruption, and perceived public expectations, often leading to the reflection of a change in their perception of selves (Radley, 1993; Snape, 2015). For example, an anonymous narrative referenced being “bruised — like a bruised peach — for life” (Anonymous in Schachter, 2008, p.36). Those living with illness may often perceive stigma if they are unable to portray the identities they believe to be expected of them. Stigma is defined as a loss of status and a disempowerment experienced by individuals as a result of the “possession of an attribute,” in this circumstance a health condition, which has been defined by cultural norms as undesirably different (Goffman, 1963; Jacoby, Snape & Baker, 2005; Scambler & Hopkins, 1986). Jacoby and colleagues (2005) report on the high prevalence of perceived stigma in those with epilepsy, and given the presence of this concept in certain narratives collected for this study, this concept will be discussed further in the *Analysis* sections. Faircloth (1998b) describes the way in which people with epilepsy use strategic communicative tools, which may include metaphor, to present identities that they perceive as acceptable to other members of society: “The control of social information through signs, symbols, and audience segregation is pivotal to the everyday management of a discreditable stigma by an individual in the social world” (p. 221).

Radley (1993) suggests that individuals react to illness by “framing” their experiences within not one isolated category or metaphor but on a domain of experience. Individuals who

attempt to normalize their illness retain their lifestyle by minimizing symptoms and marginalizing the effects (Radley, 1993). By using a literal or mechanical metaphor, the individual maintains their same identity and objectifies the illness, resulting in something external and without personal responsibility (Radley, 1993). One example of such a metaphor was given by a participant: “My brain works like a computer and seizures are like a computer crashing” (Clark, personal communication, January 24, 2012). In contrast, individuals who accommodate to an illness tend to use integral metaphors in which they can re-evaluate necessary changes in their whole lifestyle due to illness and re-construct an integrated sense of identity (Radley, 1994). An example would be, “It’s weird that something so intimate and so comfortable for me scares people so. I have the best-known type of seizure, the type everyone thinks of when they hear the word epilepsy. I flop like a fish out of water” (Anonymous in Schachter, 2008, p. 103). While Radley (1993) lays out these two distinct reactions and metaphor uses in response to illness, a range of responses would be anticipated with these two uses at each extreme. Illness narratives often involve narrators who describe an “illness identity” which they may associate with illness-related experiences. As such, I will be analyzing the selves and identities conceptualized in epilepsy narratives, with the understanding that these identities are constituted by the collection of narratives.

2.3 Metaphor Use in Epilepsy Narratives

Biomedically, epilepsy is diagnosed as a *disease*, based on undesirable physical changes, primarily the characteristic seizures and the underlying neurophysiology responsible for the seizures (Blume et al., 2001). In 2014, the International League Against Epilepsy (ILAE) continued to revise its working definition of epilepsy, and has most refined its terminology to clarify that, while epilepsy has been considered a “family of disorders” based on its

heterogeneous presentations, it must still be considered a disease, so as to ensure that the public understands both epilepsy and its severity as a disease (Fisher, Acevedo, Arzimanoglou et al., 2014). Management of the disease, involving physician diagnosis and treatment, occurs primarily in a biomedical context (Kleinman, 1988; Schneider & Conrad, 1981, 1983). Nonetheless, biomedical researchers and physicians are becoming increasingly aware of the broad implications of epilepsy diagnosis and treatment for individuals beyond the biomedical realm: “Definitions have consequences. From the viewpoint of the patient, epilepsy is associated with stigma and psychological, social, cognitive, and economic repercussions so important as to be built into the conceptual definition of epilepsy” (Fisher, Acevedo, Arzimanoglou et al., 2014, p. 479).

Psychosocially, the experience of epilepsy is identified as an illness, involving social meanings, experiences, relationships and actions that occur in relation to the disease (Kleinman, 1988). As with any chronic illness, meanings of epilepsy are heavily influenced by the medical disease process, but the subjective experiences of living with the illness are what determines their meanings, which has led to the prioritizing of the “insider’s view” in illness narrative research (e.g., Charmaz, 1991; Frank, 1995; Good & del Vecchio Good, 1994; Kleinman, 1988; Schneider & Conrad, 1983). The current study seeks to understand how people with epilepsy make meaning of epilepsy in similar and different ways and the roles that it plays in their identities within their social worlds, and epilepsy will therefore be referred to as an illness.

Epilepsy can be a particularly disruptive illness as individuals experience increased vulnerability due to unpredictable seizures in which one loses control mentally and physically. These events often leave individuals trying to regain control of their lives by making meaning of these new experiences. In reference to the experience of epilepsy, Schneider and Conrad (1983) state that: “people bring order to a disordered situation by bringing familiar frames of reference or meaning to the problematic event” (p. 56). Beginning with the presentation of the first

symptom, often the first seizure, people with epilepsy are attempting to make meaning of their experience (Velissaris, Wilson, Saling, et al., 2007). The interpretation of physical sensations, including loss of consciousness, can be extremely difficult to communicate given that the individual may not be consciously present during certain types of seizure (Faircloth, 1998a).

As a practicing physician and academic in literary studies, Rita Charon (2006) provides a useful description that helps to illustrate the difficulty that people with epilepsy may experience when trying to make sense of and communicate their physical experiences:

Even though the body is material, its communications are always representations, mediated by sensations and the meanings ascribed to them. It is sometimes as if the body speaks a foreign language, relying on bilingual others to translate, interpret, or in some way make transparent what it means to say (p. 87).

Patients and physicians often work together in an attempt to translate and interpret physical experiences associated with epilepsy, in order to arrive at a medical explanation. Diagnosis often signifies a move from the disorganized stage of the illness to an organized and prescribed course of action (Charon, 2006), which can provide both comfort and the opportunity to re-interpret past experiences (Charmaz, 1991; Schneider & Conrad, 1983). A negative aspect of medical diagnosis ascribed to individuals can be a symbolic loss of control, as individuals may lose their own illness story to the medical system if their diagnosis is accompanied by prescribed timelines and medical routines (Charon, 2006). People with epilepsy often adopt language use, especially familiar metaphors, to help make meaning of the complex biomedical and often unfamiliar information to which they are exposed (Becker, 1997; Elliot et al., 2005). Ultimately, metaphor provides a bridge from the individuals' physical and psychological experiences to that which is communicated to others (Radley, 1994). The events described through metaphor may be impacted by the individuals' misunderstandings regarding their epilepsy, based on culturally-

prevalent views or unclear conceptions of medical terms (Price, 1987, p. 784; as cited in Denzin & Lincoln, 2000). Let us now consider the historical and current biomedical conceptualizations of epilepsy that have led to culturally prevalent metaphors and interpretations of this illness.

2.4 Conceptualizations of Epilepsy

Despite a diversity of cultural beliefs, four main conceptualizations about epilepsy remain prevalent worldwide: 1) epilepsy as possession or bewitchment; 2) epilepsy as punishment for sin; 3) epilepsy as a contagious disease; and 4) epilepsy as a disease of the brain (Andermann, 2000). Though many historical beliefs have come to be proven untrue, the use of such metaphors by both the public and those with epilepsy continues (Andermann, 2000; Schneider & Conrad, 1983; Temkin, 1994). Epilepsy is usually conceptualized as a biomedical disease in Western cultures, though socio-historical conceptualizations persist in individuals' accounts of epilepsy. Here, we will briefly review the diverse conceptualizations of epilepsy that have existed, and continue to exist, over time.

2.4.1 Epilepsy in history. On the Sacred Disease, written by the physician Hippocrates around 400 B.C., is the first record of epilepsy as a physiological disease; however, the title of his seminal text reflects the popular cultural view at the time that this illness was attributed to possession by gods (Stirling, 2010; Temkin, 1994). Despite Hippocrates' early writings on epilepsy as a consequence of brain disturbance, and a disease treatable through drugs and diet rather than magic, diverse theories and beliefs regarding epilepsy prevailed (Temkin, 1994). Epilepsy metaphors and misconceptions have thus been socialized from early times as society members have attempted to make meaning of this illness. For example, early concepts of epilepsy in the Middle Ages involved references to "animalistic nature" and "lunacy" with the belief that individuals' behaviour was controlled by the moon, and leading to later associations with insanity

(Stirling, 2010). Next, references were made to “the falling sickness” and “demonic possession,” based on the belief that an evil spirit had taken over and was punishing people with epilepsy (Temkin, 1994). In the nineteenth century, despite improvement in medical understanding and treatment, people with epilepsy were often sent to asylums under the belief that epilepsy involved “uncontrolled rage” or “hysteria” that could be associated with criminal behaviour (Temkin, 1994). Despite the fact that these historical beliefs reflect folklore rather than fact, many of these terms remain a part of modern discourse. Researchers (Scambler, 1989; Snape, 2015) argue that, without a scientific explanation of epilepsy, these interpretations were the most reliable resource that societies could turn to.

2.4.2 Epilepsy in biomedicine. The current biomedical understanding of epilepsy is that of a chronic neurological disease characterized by recurrent unprovoked seizures (Blume et al., 2001). Seizures are identified as the consequence of an abnormality in brain structure or function, though in two thirds of epilepsy cases the cause of the abnormality cannot be identified (Wiebe, Camfield, Jetté, & Burneo, 2009). There exist over 15 different types of seizure, leading to insistence that epilepsy be considered a “family of disorders” or “the epilepsies” so as to capture the heterogeneous presentation of this diagnostic label (Fisher et al., 2014; Stirling, 2010). For the sake of simplicity, the multiple presentations and conditions that constitute “the epilepsies” are typically referred to as “epilepsy” and this is my practice throughout this dissertation. While approximately half of people with epilepsy experience visible tonic clonic seizures, another half of the epilepsy population may experience less visible seizure types (Berg, Berkovic, Brodie, et al., 2010). While the ILAE is in the process of revising its seizure terminology, Appendix B provides a summary of past and current epilepsy terminology adapted from ILAE publications

(Fisher, Van Emde Boas, Blume, et al., 2010; Fisher et al., 2014; Scheffer, Berkovic, Capovilla, et al., 2014).

Medical treatment of epilepsy involves anticonvulsant pharmaceuticals and surgery, through which 65-75% of patients achieve seizure control (Blume et al., 2001; Wiebe et al., 2009). There has long been the recognition that epilepsy can have a significant impact on an individual's quality of life, and thus substantial effort has been put into developing measures to assess health beyond seizure control (Jacoby, Snape, & Baker, 2009). People with epilepsy are two to three times more likely to experience a psychiatric disturbance, most frequently involving anxiety and depression (Wiebe et al., 2009). Psychiatric disturbances have been associated with both biomedical and psychosocial causes including poor seizure control, cognitive difficulties, impaired social functioning, and poor self-perception (Jacoby et al., 1996, 2009). Jacoby and colleagues (2005) argue that public perception of epilepsy does not reflect the diversity of the disease, with epilepsy most often perceived as a solely physical disease involving the occurrence of visible seizures, as well as chronic and incapacitating physical limitations.

It is important to recognize the language with which epilepsy is associated and communicated, as these are the terms with which individuals make meaning. Here I will turn to epilepsy narrative research, involving the collection of anonymous epilepsy narratives, in order to take into account the linguistic and narrative approaches used by individuals with epilepsy, as co-constructed and informed by socio-historical and medical forums.

2.5 Epilepsy Narrative Research

Diagnosis with any chronic illness creates a biographical disruption in which individuals often resort to narrativization in order to make meaning of their illness and to re-construct an identity that includes their illness (Frank, 1995; Good, 1994; Kleinman, 1988). In the 1980s and

early 1990s, sociologists and medical anthropologists presented several theories regarding epilepsy narratives, with a primary focus on individual and social perceptions of epilepsy and identity (Good & del Vecchio Good, 1994; Kirchglässer, 1990; Kleinman, Wang, Li, Cheng, Dai, Lee, et al., 1995; Scambler & Hopkins, 1990; Schneider & Conrad, 1983). These studies reviewed the narratives as a whole, with minimal attention directed specifically to metaphor use or the role of metaphors in the narratives. A few researchers have since reviewed and expanded upon these theories of illness identity but much research focus has shifted towards biomedical improvements in epilepsy care (Jacoby, Snape, & Baker, 2009; Kiliç & Campbell, 2009; Faircloth, 1998a; Scambler, 1998). While theorists continue to acknowledge the importance of psychosocial factors in coping with epilepsy, many such factors have come to be part of the biomedical model and are often addressed through quantified measures that may not account for the diversity of individual experiences (Devinsky et al., 1995; Elliot, Lach, & Smith, 2005; Jacoby et al., 2009). The following section will review past qualitative research on epilepsy narratives beginning with its early role as a model of a stigmatized illness, and seizures as a model of “deviant behaviour” (Schneider & Conrad, 1981). Next, a review of the different typologies of epilepsy narrative, categorized by individuals’ understanding and communication of their epilepsy experiences, will be reviewed as groundwork that will be revisited throughout the *Analysis* chapters. Consideration and comparison of different epilepsy narrative terminologies and typologies will help to highlight their utility in understanding experiences of epilepsy and will also draw focus to areas where attention to metaphor could prove useful.

2.5.1 Epilepsy narrative research and stigma. It is important to note the history of studies on epilepsy narratives, many of which were carried out to gain insight into an illness that had been identified as highly stigmatized (e.g., Good & del Vecchio Good, 1994; Kleinman, Wang, Li, Cheng, Dai, Lee, et al., 1995; Scambler & Hopkins, 1990; Schneider & Conrad, 1983).

Goffman (1963) referred to stigma as a loss of status or disempowerment that individuals may experience as a result of the possession of an attribute, in this circumstance a health condition, which has been defined by a culture to be undesirably different. A report commissioned by the ILAE and World Health Organization (WHO) identified that stigma against epilepsy remains high in developed — and even more so in developing — countries (Theodore et al., 2006). An important distinction has been suggested between *enacted stigma*, in which individuals experience social discrimination as a result of having epilepsy (such as in interpersonal or institutional contexts), and *felt stigma*, in which individuals may experience internalized shame of having epilepsy and fear of encountering stigmatization (Scambler & Hopkins, 1990; Muhlbauer, 2002; Kiliñç & Campbell, 2009). In *Illness as Metaphor* and *AIDS and Its Metaphors*, Sontag (1977, 1988) suggested that stigma towards illness is frequently reflected in the metaphors with which members of a society try to make sense of an illness, borrowing from source experiences with which individuals have prior experience to label or explain a less familiar target (e.g., cancer, AIDS). Sontag (1977) theorized that advances in treatment accompanied by accessible explanations and terminology would lead to de-stigmatization of illness, as was seen with leprosy and tuberculosis. While the biomedical understanding of epilepsy has improved, the continued use of folklore-based or other inaccurate epilepsy metaphors may be confusing to people with epilepsy and may lead to the perception of stigma. Schneider and Conrad (1980) emphasize that it is the felt stigma — that is, the perception of stigma — that is of relevance, emphasizing that having epilepsy does not automatically cause stigma. Rather, the manner in which individuals make sense of their illness, including anticipated social responses, must be prioritized in determining the role that the illness plays in an individual's concept of illness and self (Schneider & Conrad, 1983). In their 1990 study, Scambler and Hopkins identified that felt stigma was reported three times more often than enacted stigma. Later studies have identified lower-reported

levels of felt stigma; however, they also identified that the stress of managing and hiding epilepsy was significantly more disruptive than the seizures themselves (Jacoby, Snape, & Baker, 2005). The perceived need to manage personal information, including possibly hiding one's illness due to perceived stigma, can play a central role in identity re-construction and reflection on individuals' personal narratives.

2.5.2 Epilepsy narrative research and epilepsy typologies. In *Having Epilepsy*, Schneider and Conrad (1983) review the stories of over 80 people with epilepsy and provide us with significant insight regarding the impact of epilepsy on identity. The researchers state their primary goal as attempting to gain an "insider's perspective" on an illness that, at the time, had been minimally studied from a sociological perspective. They argue that while the medical epilepsy typologies are based on characteristic seizure patterns and neurophysiology, sociological epilepsy typologies have been identified based on how people with epilepsy define and communicate their medical, social, and personal experiences of the illness (Schneider & Conrad, 1981, 1983). The four sociological epilepsy typologies identified were: "unadjusted," "secret," "pragmatic," and "quasi-liberated." The first group, the "unadjusted group," was identified as people debilitated by epilepsy based on their inability to accept or to discuss their illness. The next three groups were identified as having "adjusted" to their epilepsy but were separated based on the different identities and coping strategies that people had constructed, as conveyed in their illness narratives. The "secret" group was seen as having accepted their epilepsy but were unwilling to disclose information to anyone other than their treating physicians. The "pragmatic" group was seen as having accepted their epilepsy and discussed it only with those individuals who they deemed necessary to tell, such as their physicians, families, and possibly employers. Finally, the "quasi-liberated" group of people were characterized as eager to discuss their

epilepsy with others, interpreted as a means to educate others as well as to minimize their personal burden of epilepsy by gaining social support (Schneider & Conrad, 1981, 1983). Though not a primary focus for the researchers, quotes from the individual narratives are abundant with metaphors and many metaphors centred on identity negotiation in relation to both physical disturbances, primarily seizures, and social consequences, primarily perceived epilepsy-related stigma (Schneider & Conrad, 1981, 1983). The central role of stigma in epilepsy experiences has been found across cultures, with widespread identification of “information management” in which individuals or families were selective as to when and with whom they share epilepsy-related information (Good & del Vecchio Good, 1994; Kleinman, Wang, Li, Cheng, Dai, Lee, et al., 1995; Scambler & Hopkins, 1986). While Schneider and Conrad identified three groups who had “adjusted” to their epilepsy, I was surprised by the level of information management that was presented, with only the “quasi-liberated” group reportedly sharing their illness beyond a need-to-know basis. These findings overall suggested a level of secrecy and perceived vulnerability that would likely minimize the opportunity for dialogue, and which I suspected were a reflection of the time period and cultures considered. Nonetheless, future studies have continued to identify social epilepsy typologies similar to Schneider and Conrad’s, particularly in portrayals of communication and identity control as playing a central role in narratives of epilepsy (Kiliñç & Campbell, 2009).

After a diagnosis of a chronic or severe illness, a common reaction is to hide the illness from others until the individual has had the opportunity to renegotiate his or her social identity (Charmaz, 1991; Kleinman, 1988; Scambler & Hopkins, 1986). In epilepsy, identity negotiation is seen as a long-term process in which divulgence to select people, with simultaneous concealment from others, is intricately involved (Schneider & Conrad, 1981, 1983; Kiliñç and

Campbell, 2009). Recent research by Kili  and Campbell (2009) indicated that healthy re-negotiation of social identities was dependent on three factors: 1) level of accurate understanding of disease processes, ranging from misconceptions to ownership of epilepsy-related experiences; 2) level of acceptance, ranging from avoidance of diagnosis to sharing one's epilepsy experiences; and 3) level of comfort, ranging from embarrassment to normalization of epilepsy as part of their identity (Kili  & Campbell, 2009). While Kili  and Campbell did not label their groups, the outcomes were markedly similar to Schneider and Conrad's groupings with the primary focus of how positioning along the three factor spectrums (e.g., levels of accurate understanding, acceptance, and comfort) played a role in identifying the groups. Many of the people with epilepsy interviewed believed that misconceptions were prevalent, which were seen to perpetuate their felt stigma and their fear of diagnosis, which was perceived to distance them from the "normal" population (Kili  & Campbell, 2009). One group of individuals, who could be considered akin to Schneider and Conrad's "unadjusted" group, were unable to adjust to or share their illness with others, describing epilepsy as their "cross to bear" with identities expressed as "overcome" and "flooded" by epilepsy (Kili  & Campbell, 2009). A second group of individuals also held negative beliefs but demonstrated some adjustment to their illness. This group still chose to conceal their epilepsy from others, similar to Schneider and Conrad's "secret" group; many described elaborate concealment strategies and rationalized that they "want to be judged as a person and not as someone with epilepsy" (Kili  & Campbell, 2009). The third group, comparable to Schneider and Conrad's "pragmatic" group, disclosed their epilepsy only when needed as they "don't want to wear it as a label." Healthy adjustment was identified by the individual's ability to take personal ownership, out of a sense of independently learned control of seizures (Kili  & Campbell, 2009). Finally, a fourth group, similar to Schneider & Conrad's "quasi-liberated" group, was described as those who disclosed their epilepsy to process their

concerns surrounding illness (Kiliñç & Campbell, 2009). It is noteworthy that felt stigma and identity management were not the original focus of Kiliñç and Campbell's (2009) study, but rather became focal when these aspects were identified by participants as central to their experiences with epilepsy. While Kiliñç and Campbell (2009) identified awareness of Schneider and Conrad's research (1983), it is surprising and somewhat disappointing that these four similar typologies remain over 25 years later, with both studies identifying four epilepsy conceptualizations in which only one group openly shared their illness experience. Again notable is the fact that, while metaphor was not a focus in this more recent study, multiple narrative excerpts were provided in which individuals clearly utilized metaphor in conveying their conceptualizations of self and of epilepsy.

Kirchglässer (1990) proposed a model identifying three types of "lay theories" in which people with epilepsy make sense of their experiences. His model identified some conceptualizations that were presented in the sociological typologies discussed above, but focused even more so on terminology that individuals appeared to utilize in making sense of, and possibly adjusting to, their epilepsy experience. I was particularly interested in his findings for the terminologies and the purported origins of these terminologies. Kirchglässer (1990) referred to these three theories as "social constructions of reality with a high degree of logical coherence, that possess a complex relationship to biomedical theories of epilepsy" (p. 1314). First, in the "medical illness theory," people with epilepsy present their experiences using the formal medical discourse and medical narrative timelines they learned while undergoing medical treatment (Kirchglässer, 1990). Kirchglässer (1990) interpreted the use of medical terminology and medical narrative approaches as associated with a negative focus on epilepsy, such as fixating on the chronicity and pervasiveness of the illness. Others have presented individuals' education and use of medical terminology as leading to perceived empowerment and control of their illness

(Kirmayer, 2000), while it has also been presented as a distancing individuals' identity from an illness experience over which the biomedical community takes ownership (Radley, 1993).

Kirchglässer's second proposed lay theory is the "life-world illness theory," in which people with epilepsy interpret seizures in the context of their biographical background and daily experiences, attributing a causal role for their illness experiences to events in their personal history (Kirchglässer, 1990). These individuals tended to avoid biomedical terminology to describe seizures and their causes, and rarely use the term "epilepsy" (Kirchglässer, 1990). This group reportedly used personally-meaningful terms, with "electricity" identified as a popular metaphor used between patients and their physicians (Kirchglässer, 1990). Of interest to me here was the fact that, while "electricity" was identified as a term introduced by the patients, it has a long history in the social history of epilepsy and has often been more so associated with the medical community (Temkin, 1994). Third, in the "mixed illness theory," aspects of both medical and life-world terminology are utilized (Kirchglässer, 1990). Individuals report seizures and illness experiences according to biographical background but demonstrate reasoning that integrated medical and social influences determine their health (Kirchglässer, 1990). This group in particular tend to favour psychosomatic disturbances, particularly social and physical stressors, as responsible for triggering seizures. Kirchglässer (1990) concluded that those who were able to develop their own interpretation of their epilepsy — through mutual understandings with their physicians, endorsement of their beliefs regarding psychosomatic stressors, and significant re-interpretation of their life-worlds after diagnosis — were most likely to accept and integrate the diagnosis of epilepsy. Kirchglässer's three theories suggest unique roles for medical, socio-historical, and individualized beliefs in conceptualizing epilepsy and its impact on identity, with communication occurring through language particular to each of these sources.

In Kirchglässer's lay theories of epilepsy, great value is placed on the terminology used by participants in their evolving conceptualizations of epilepsy as it relates to their own life-worlds. This approach provided one more frame from which to consider the participants' metaphors, particularly the possible evolution of what they identified as medical terminology; it had me re-evaluating the roles that same metaphor can play for different individuals or at different times for the same individual. Kirchglässer's emphasis on mutual understanding and endorsement of individuals' beliefs as means to facilitate their acceptance and integration of epilepsy identities, again highlighted for me the importance of acknowledging and considering each individual's unique language use. While Schneider and Conrad (1981, 1983) and Kiliç and Campbell (2009) provide categorization of epilepsy conceptualizations related to adjustment to life with epilepsy, Kirchglässer (1990) highlights the diverse ways in which language use both mediates and communicates these developing conceptualizations. He further discusses how observation of changes in language use, as well as efforts to appreciate unique meanings over trends, can reflect adjustment to life with epilepsy. This emphasis of the diverse meanings for what may otherwise be considered common terms in epilepsy dialogues was particularly relevant for me in considering narratives in which medical terminologies seemed to play a unique role.

Another product of epilepsy narrative research are Scambler's extensive writings on the topic of epilepsy and identity management (e.g., Scambler & Hopkins, 1986, 1990; Scambler, 1993, 1994, 1998). Scambler (1993) proposed five dimensions to coping with chronic illness, two of which are particularly relevant to my study of language use in conceptualizing and communicating experiences of epilepsy. First, rationalization involves individuals' need to make sense of illness experiences and illness identities (Scambler, 1993). Second, gaining clear concepts of self includes developing clear conceptions of identities and self-worth, both likely to be impacted by the individuals' perception of stigma (Scambler, 1993). Both rationalization of

illness experiences and conceptualizations of one's identity could be addressed by the use of metaphor and narrative through the formation of a coherent understanding of illness and identity. While not directly related, the three additional dimensions of coping are likely to involve some degree of metaphor and narrative use. These include accommodation to the physical consequences of epilepsy, maintenance of healthy social relationships, and achieving a sense of fulfillment in social and occupational roles (Scambler, 1993, 1998).

2.5.3 Epilepsy narrative research: Family perspectives. A study that built on the research of Schneider and Conrad (1983) was that carried out by West (1985), and revisited and supported later by more recent research (Elliot et al., 2005; Jacoby & Austin, 2007; Ronen, Rosenbaum, Law, & Streiner, 2001; Ronen, Streiner, & Rosenbaum, 2003), in which narratives were collected to understand the experience of families living with epilepsy. In the case of those diagnosed in childhood and adolescence, individuals are reliant on family and peer perspectives to form their sense of identity as impacted by epilepsy (Ronen, Rosenbaum, Law, & Streiner, 2001; Ronen, Streiner, & Rosenbaum, 2003). Though it has become less common, many parents conceal a child's epilepsy, leaving individuals either unaware of their own diagnosis or, more commonly, with the perception that their epilepsy is an unacceptable "secret" (Schneider & Conrad, 1983; West, 1985; Ronen et al., 2001). Alternatively, parents may avoid circumstances in which they believe their child's condition could be discovered, leading to withdrawing a child from certain physical or social activities (Elliot et al., 2005; Ronen et al., 2001; Schneider & Conrad, 1983; West, 1985). Still other parents chose an "avowal of normality" in which they disclose their child's condition in order to reduce any risk of injury, as well as to maintain an identity as close as possible to "normal" for their child (Schneider & Conrad, 1983; West, 1985; Ronen et al., 2001). Given that each of these three strategies involve management of a child's identity and social exposure, development of the illness identity is constrained to those resources

that the parent has made available. As such, individuals who live with epilepsy in their youth may negotiate an identity within this framework and might be confronted with the need to re-conceptualize illness as they age. Thus, illness and identity construction in this population becomes largely dependent on interpersonal interactions, with later influences of medical terminology once individuals are old enough to be involved in medical conversations regarding their epilepsy. While these studies targeted parental perspectives and family dynamics specific to children and adolescents with epilepsy, these findings helped me attend to the varied roles that family members may play in epilepsy experiences for all of the participants, including those diagnosed in adolescence and those diagnosed in adulthood.

2.5.4 Epilepsy conceptualizations: Defining epilepsy. Rätty and colleagues (2009) carried out a study with people with epilepsy and narrowed the focus from more elaborate narratives to participants' cognitive conceptualizations based on the question: "*What is epilepsy?*" Though not identified as such, the vast majority of responses involved images and metaphors. The six conceptions of epilepsy held by people with epilepsy were identified as: 1) an illness related to a physical disturbance; 2) a condition related to a physical disturbance; 3) a mental disturbance related to a lack of mental capacity; 4) a handicap related to psychosocial aspects of the illness; 5) an identity related to being "epileptic;" and 6) punishment (Rätty et al., 2009). In the first two conceptualizations, patients described their epilepsy as equivalent to a physical disturbance, most often solely the seizures experienced (Rätty et al., 2009). Interestingly, positive emotions such as relief and confidence were associated with these seizure-related conceptualizations (Rätty et al., 2007, 2009). In contrast, the remaining conceptualizations, which focused on psychosocial deficits and negative concepts of identity, were associated with negative emotions such as fear, shame, and sorrow (Rätty et al., 2007, 2009). Emphasizing the

“invisibility” of the condition in social arenas and reinforcing previous research, the majority of participants identified psychosocial difficulties as a more central conceptualization than the physical seizures experienced in epilepsy (Bishop & Allen, 2003; Jacoby, Snape, & Baker, 2005; Rätty et al., 2009). These psychosocial difficulties included increased psychological distress, lower self-esteem, negative concept of oneself, negative concept of one’s physical condition, and interpersonal difficulties (Jacoby, Baker, Steen, Potts, & Chadwick, 1996; Jacoby, 2002; Jacoby et al., 2005; Rätty, Söderfeldt, & Larsson, 2007; Rätty et al., 2009). These conceptualizations addressed the domains of Leventhal and colleagues (2001), though greater focus appeared on the illness identity and social consequences than on other aspects of the illness (e.g., timeline, controllability).

2.5.5 Epilepsy narrative research: Summary. By reviewing epilepsy narratives, we can gain a clearer understanding of the way in which people with epilepsy use metaphors to make meaning of their illness and re-construct their identity. The metaphors used — as well as the context in which they are used — may help to indicate why perceptions of stigma have retained a role in identity re-construction for people with epilepsy. Next, a review of metaphor as a linguistic resource in seizure descriptions helps to illustrate ongoing research in epilepsy, particularly surrounding the importance and utility of examining language and narrative encounters that illustrate the central role of metaphor in epilepsy conversations.

2.6 Epilepsy Narratives and Seizure Metaphors

As the most visible and most biomedically significant aspect of epilepsy, seizures and the meanings attributed to them are central to the overall experience of epilepsy described. In the next section, we will consider seizure-specific metaphors as they were observed in patient-physician discourses reported in the literature. The primary finding of a focus on control in these

metaphors connects well with my findings from the studied narratives, which focused heavily on perceived loss of control and metaphors that seemed to represent attempts to gain control.

A German EpiLing project involved analysis of the metaphors used by people with epilepsy to describe their experiences of seizures (Monzoni & Reuber, 2009; Plug, Sharrack, & Reuber, 2009a, 2011; Schwabe, Howell, & Reuber, 2007; Schwabe, Reuber, Schöndienst, & Gülich, 2008; Surmann, 2005). A primary goal was to determine whether, based on their metaphor use, patients with epileptic seizures could be differentiated from those experiencing psychogenic nonepileptic seizures (PNES; Schwabe et al., 2007). PNES may present as epileptic seizures to the public but, to experienced clinicians, they often appear physically different in the movements involved and are not accompanied by the same changes in brain activity, as determined by electroencephalographic changes, seen during an epileptic seizure (Reuber & Elger, 2003). PNES are psychological in origin, though an estimated 70-75% of cases are initially misdiagnosed as epilepsy (Reuber & Elger, 2003). Improvements in differentiating patient experiences are hoped to lead to improved diagnostic accuracy (Reuber & Elger, 2003; Plug et al., 2009a).

The project involved conversation analysis of patient-physician interactions, with the goal of improving physician accuracy and understanding of seizure experiences. The study explicitly identified that a typical patient-physician interaction tended to be directed by physicians' questions and interests, and instead directed physicians to lend themselves to a patient-directed presentation of their seizure experiences. Emphasis was given to *how* the patients chose to convey their experiences, acknowledging the intersubjective process. In turn, it was suggested that physicians change focus from what they think is relevant (i.e., *what* patients say) to what patients present as relevant (i.e., *how* and *when* patients say it; Schwabe et al., 2007). The research identified distinct communication profiles for patients with epileptic seizures and

patients experiencing PNES (Schwabe et al., 2007; 2008), with neurologists' diagnostic accuracy of epileptic seizures highly correlated with specific metaphor patterns identified by linguists (Plug et al., 2009a). People with epilepsy displayed significantly more effort in formulating a coherent, detailed account to ensure intersubjective understanding of their seizure experiences (Schwabe et al., 2008). People with epilepsy were also found to be more consistent with the metaphors they used to conceptualize and communicate their seizures; these individuals frequently used metaphors in reference to "external forces," as will be discussed below (Schwabe et al., 2008; Surmann, 2005).

A follow-up analysis focused on the types of metaphors used to describe seizure experiences, seeking to create a typology of metaphors that could distinguish those patients experiencing epileptic seizures from those experiencing psychogenic non-epileptic seizures (PNES; Plug et al., 2009c). The researchers defined metaphor in accordance with Lakoff and Johnson's theory (CMT; 1980) as: "an expression used in one semantic field while the core meaning lies in another" (Plug et al., 2009b, p. 996). Three main conceptualizations of seizures were grouped according to metaphor types; a seizure experience was characterized as an event/situation, an agent/force, or a space/place (Plug et al., 2009b). While all patients tended to use to all metaphor types, patients experiencing epileptic seizures more frequently identified their seizures as an external event or agent, suggesting an external locus of control (Plug et al., 2009a; Schwabe et al., 2007). In contrast, patients found to be experiencing PNES had a tendency to describe seizures as a place or space that they moved through (Plug et al., 2009a; Schwabe et al., 2007). Thus, the majority of metaphors used by people with epilepsy contextualized patients as not in control of their experience, and consisted of three main elements that conveyed seizures as either: 1) an entity that acts of its own volition; 2) an enemy that must be fought against; or 3) an external threat (Plug et al., 2011; Surmann, 2005; Schwabe et al., 2007).

All patients described a “phase of reduced self-control,” involving loss of physical control and of consciousness, as part of their seizure experience (Schwabe et al., 2007). Given this “gap” in time for which the people experiencing seizures were not consciously present, they had little recollection of the events and spent much of their assessment attempting to re-construct what had occurred (Schwabe et al., 2007; Surmann, 2005). Many patients initiated the conversation by identifying how it was hard to describe seizure events, followed by recurrent attempts to re-construct seizure episodes in ways that made it clear they had been understood by the listener, in this case a neurologist or their research assistant (Schwabe et al., 2007; Surmann, 2005). The EpiLing project has identified a range of seizure metaphors that are being considered for diagnostic screening purposes, providing neurologists with a new strategy to differentiate seizure typology based on attending to patient descriptions and metaphors (Schwabe et al., 2008). For the purpose of my study, the exploration of metaphors describing “reduced self-control” and attempts to convey the “gap” in time were particularly useful, as multiple participants described epilepsy conceptualizations that seemed to stem from these seizure-related experiences.

Researchers highlight the utility of metaphors — and effective verbal communication more broadly — to identify differences in patients’ concepts of illness, self, and coping strategies (Monzoni & Reuber, 2009; Schwabe et al., 2008; Spector et al., 2000). Monzoni and Reuber (2009), employing thematic analysis, observed epilepsy patients who normalized their illness and presented as “in control”; however, their more in-depth interactional and linguistic analysis identified individuals who struggled with control given their use of less-effective coping strategies. It has recently been acknowledged therefore that metaphors used in patient conceptualizations of epilepsy, as well as metaphors used in reference to seizures specifically, are key in gaining insight to patient experiences (e.g., Rätty, Larsson, Starrin, & Larsson, 2009; Surmann, 2005). With this acknowledgement in mind, my research targeted these seizure and

epilepsy metaphors to address not diagnostic strategies for seizures, but to gain an understanding of seizure and epilepsy conceptualizations that play a role in concepts of illness and identity.

Having considered past epilepsy narrative research followed by a narrowed focus on seizure and epilepsy metaphors, I will next consider published narratives that I sought out in an attempt observe individual epilepsy narratives and the ways in which these edited, published accounts might differ from those collected for research purposes. Let us now consider select published accounts to provide insight into the different metaphors, including socio-historical and biomedical terminology, that appear to be in use.

2.7 Published Epilepsy Narratives

In an attempt to familiarize myself with epilepsy narratives and some of the language currently being used in epilepsy storytelling, I explored published autobiographies and memoirs (see Appendix A: Published Narratives). I also read published biographies as well as a few publications that blur the edge of fiction/non-fiction even further than the traditional degree of fictionality that would naturally be expected of any recounted story (e.g., Slater, 2000). These biographies and stories enabled me to gain a larger sense of public perspectives from family members of individuals with epilepsy. While these were not the focus of my analysis, they did help to familiarize me with common narrative themes and lingo that I might encounter in the written and oral narratives I later collected. They provided me with one more angle on epilepsy narratives, as I was able to consider published epilepsy narratives (e.g., autobiographies and biographies) as compared to research publications (e.g., analyses of anonymous epilepsy narratives, or non-narrative based epilepsy research), as well as in the context of clinical encounters and interactions with an epilepsy community group.

2.7.1 Published epilepsy narratives: Changes in epilepsy narrative forms. A quick realization in searching for texts about personal experiences with epilepsy was that they were much less common than those written by individuals with other illnesses. Coming from a research team that was examining cancer narratives for example, my search narrowed from entire bookstore sections that held 20 or more titles related to cancer autobiographies, to a selection of one or two epilepsy autobiographies at most. Searching online, I found approximately 20 titles under “epilepsy autobiographies” and “epilepsy memoirs” in 2010. While this could reflect the relative incidence of epilepsy in the general population (0.5-1%), searches for autobiographies and memoirs from individuals with other chronic illnesses retrieved hundreds of titles despite their comparable incidence in the general population [e.g., diabetes (2-3%), multiple sclerosis (0.03-0.08%), autism spectrum disorders (0.1-0.6%)]. While several factors can and certainly do play a role in this discrepancy, I would like to draw attention to one factor in particular that that I became aware of over the course of my writing.

The number of autobiographies on epilepsy published since my initial search in 2010 has more than doubled in the past seven years (2017). A noteworthy addition to this finding is the fact that of the approximately 50 autobiographies published in the past seven years, the vast majority have been written by individuals who describe themselves as “survivors” or individuals who have “overcome” their epilepsy. This rise in publications is interesting to consider for a few reasons. First of all, past studies of epilepsy narratives often yielded “chaos narratives” from those who had not yet found a successful treatment, due to the fact that their seizures are newly presenting or the fact that their seizures are difficult to control. Chaos narratives are stories of individuals who are battling an unpredictable illness, in which they are unable to find order in their “disordered” experience of time and illness trajectories (Becker, 1997; Frank, 1995). These

chaos narratives appeared to be underrepresented in the published narrative domain. At most, some of the stories I encountered involved individuals who told of narratives in which they had been able to establish some type of “cooperative” relationship with their epilepsy, identifying their health as manageable if not stable and their epilepsy as a source of motivation and direction in their lives, akin to “quest narratives” (Frank, 1995).

The recent increase in epilepsy narratives appears to reflect most closely an increase in individuals telling the story of successful epilepsy surgery, with “success” defined as the biomedical community has, through seizure control. As such, more individuals are telling “restitution narratives” in which they are able to reflect retrospectively upon their experience and to identify themselves as having been cured, or as having gained control over their illness (Frank, 1995). This has significant implications for individuals with epilepsy who may turn to the writings of their peers for a better understanding of self. Not only has the increased availability and prevalence of surgery made it a more viable option, the medical gold standard of full seizure control has meant that what could be called a “typical” epilepsy narrative has evolved. Earlier research of common epilepsy narratives, such as those carried out by Goffman (1969) and Schneider and Conrad (1983) held no mention of surgery in the trajectory of initial signs, diagnosis, and treatment with complete seizure control as the ideal outcome. The majority of research since then has focused on other aspects of the epilepsy experience, particularly stigma and quality of life, with few studies addressing the treatment trajectory itself until a recent publication by Snape (2015). Her study identified that beyond both internal controls (e.g., lifestyle choices) and external controls (e.g., expanding familial support and becoming more proactive in medical treatment), surgery exists as a step beyond the external controls most frequently perceived as opportunities to control one’s epilepsy (Snape, 2015). Snape’s finding was noteworthy and helped to reinforce my finding that these autobiographies were part of a new

wave of epilepsy “survivorship” narrative that might well result in changes to the language and narrative typologies likely to be encountered. To provide a sense of the types of metaphors and narratives that I encountered, I next review a brief sampling of those encountered in the texts that I explored.

2.7.2 Published epilepsy narratives: Sample metaphors. While a complete review of published epilepsy autobiographies is beyond the scope of the current research document, the current study did begin with an overview of epilepsy autobiographies, memoirs, and biographies, so as to gain a broader understanding of the cultural background of typical epilepsy narratives and terminology in published format. Some brief examples from the reviewed sources will help to illustrate the prevalence of metaphor use in published, modern-day epilepsy narratives. Personal accounts of epilepsy include metaphorical references to socio-historical beliefs, similar to those outlined by Temkin (1994). These include reflections of demonic possession, including individuals who feel “evil forces” or have “Satan in my soul” (David B., 2005; Kissing, 2003). Others reflect possession experiences in terms that do not identify demons but may be impacted by current events and modern discourse such as Connolly’s (2005) “invasion” of the self, and Healey (2009) who described how her mind was “taken over by a terrorist” after she started having seizures. Other narratives refer to concepts of uncontrolled rage, as discussed by Temkin, including experiences of “rage like a warrior” and “fits of rage” (David B., 2005; Fiennes, 2008; Schachter, 2003). Biomedical concepts of epilepsy are also replete with imagery. For example, physicians and patients speak of “neurons misfiring,” “electrical disturbances,” and seizures, rather than of patients who are “resistant to treatment” (Blume, 2001; Kinsman, 2007; Wiebe et al., 2009). In many of the published narratives reviewed, metaphor use by people with epilepsy is consistent with medical terminology and medical course of treatment though these may not be the dead metaphors we might expect. For example, references to electricity and seizures are prevalent

in both medical and societal discourse, perhaps leading to misunderstandings such as the “fear that I might electrocute her [after a seizure]” (Robinson, 2006). Certain individuals equate being medicated for their seizures with “living in a fog” and being “zombie-like” (Connolly, 2005; David B., 2005). Still others provide metaphors that are less commonly used in epilepsy narratives or epilepsy research, reinforcing the diversity of experiences and conceptualizations that can be held. Examples include: “living a perforated existence,” feeling like a “marionette,” and living “across the moat” from others (Anonymous *in* Schachter & Andermann, 2008; Kissing, 2003; Slater, 2000). These diverse choices of metaphor emphasize the different conceptualizations of epilepsy held by narrators, and serve as an indicator of the unique identities and narratives that are expressed. As noted, the vast majority of these personal accounts were written by individuals who have undergone surgery to control their seizures. As with many people living with chronic illness, many reference their life with epilepsy using the “journey” metaphor (Frank, 1995, 2013; Lakoff & Johnson, 1980). Some identified journeys of positive change, such as “my quest to find out the truth,” “creeping towards hopefulness,” and being “able to change lanes” (Connolly, 2005; Healey, 2009; Kinsman, 2007). Those whose seizures have been controlled by surgery or successful medication provided descriptions of “freedom from my little cave,” “blossoming into a new me,” or even individuals describing themselves as “under control” (Kinsman, 2006; McCallum, 2008).

Metaphors are not only central to making meaning of the illness identity, but they also reflect diverse experiences and understandings. That is, people with epilepsy appear to not only use a range of metaphors, but even the same metaphor can carry very different meanings depending on the person. A metaphor that one individual finds therapeutic in helping her or him to make meaning of an experience, another individual might find inaccurate, unhelpful or

upsetting. Alternatively, the tenor of one event might be clarified by metaphor; for example, one individual identified her medical treatment as a negative “barrier to normalcy” (Schachter, 2003) while another described it positively, “like winning the lottery” (Eicholz, 2009). By considering the diverse use of seizure and epilepsy metaphors in published narratives, after having grounded myself in some of the epilepsy narrative research, I was able to gain a further understanding of the different ways in which those with epilepsy may communicate their illness experience. I found a contrast between the published narratives, many of which were rife with metaphor, as compared to the excerpts from anonymous narratives that I encountered in the research. While some of the published narratives were written by professional authors, others were self-published by individuals with varied epilepsy-related and professional backgrounds. While all published narratives would have been reviewed and edited professionally, the variability in authorship and publication led me to the conclusion that metaphor was likely to present to different degrees in all published or unpublished epilepsy narratives, albeit to varied extents depending on the contextual factors at play. Having considered the literature and publications that was reviewed, let us now turn to the research design and methodology that drove my study.

CHAPTER THREE

Research Design

In the next section I outline my objectives and the methods used. I will discuss my choice to select a qualitative approach in studying epilepsy metaphors, a choice grounded in the previously discussed research on epilepsy narratives, conceptualizations of self and illness. In addressing my goals for the project, I outline the narrative analysis paradigms with which I undertook this project, beginning with the ontological and epistemological assumptions which most closely align with my approach. Finally, the bulk of this chapter involves an outline of the methods used for participant recruitment, collection of narratives, and data analysis.

3.1 Objectives

The goal of my research was to understand how people with epilepsy use linguistic resources, specifically metaphor, to conceptualize and communicate their epilepsy experiences. My approach was to identify metaphors in early readings, then further examine their context to understand how they were used within the epilepsy narratives that conveyed individuals' experiences and identities after onset and diagnosis. I anticipated that the terminology that individuals had encountered in biomedical, familial, and broader cultural perspectives may provide insight into how these different sources may impact patient conceptualizations of their own epilepsy and illness identity.

Given epilepsy's background as a condition with diverse historical and biomedical interpretations, I was keen to observe, for example, terms that might otherwise be considered "dead metaphors" based on their longstanding prevalence in cultural dialogue. As noted, it has been suggested that terms that would be considered "dead metaphors" based on socialization should still be considered as "creative metaphors," given the fact that each individual involved in

a dialogue may interpret them differently (Donoghue, 2015; Kirmayer, 1993). Kirmayer (2000) emphasizes that patients and physicians often use different “communicative codes” when discussing illness. A physician may explain or interpret a patient’s condition based on biomedical terminology, perceived by them to be a “dead metaphor” given its prevalence in the biomedical forum, while the patient’s embodied experience may lead to different interpretations and expressions (Gergen, 2015; Kirmayer, 1992). This can lead to miscommunications even when individuals are using the same terms. Many of this study’s participants noted terms that they had arrived at through interpretation and experience with one medical physician, only to be informed by another medical source that these terms were incorrect or not accurately understood. With this in mind, I frequently asked participants to elaborate on language used in order to approach a co-construction of narratives, and so as to try to avoid imposing my own assumptions of the meaning of the language being used. This occurred throughout my analysis, but can be identified primarily at two points in the research process. The first was my use of an open-ended interview guide (Appendix C) in which I prepared general questions and topics that I had in mind, but in which I also noted terminology used by participants in their written narratives so as to be mindful of terms that might arise. The second attempt to explore meanings was throughout our conversations, or oral narratives, in which I would ask participants to elaborate on a term if it was one that they appeared to rely upon frequently, one that was unclear to me in the way that they were using it, or terms that tended to be prominent in epilepsy lingo (e.g., seizure typologies, medication names) and that therefore might lead to assumptions about meaning.

3.2 Rationale for Qualitative Methodology

Several authors have indicated that, due to the heterogeneity of epilepsy experiences and illness identities, it can be difficult to investigate this topic using quantitative methods (Faircloth,

1998a; MacLoed & Austin, 2003; Nijhof, 1998; Scambler & Hopkins, 1990). Select quantitative tools have been developed in an attempt to measure objective experiences in epilepsy, and these have developed from exploratory qualitative research. Nonetheless, these tools are narrow in terms of the aspect of experience that they measure (e.g., health-related quality of life, seizure typology, etc.) and do not provide the richness of material that I was seeking to explore. As such, qualitative methods were determined to be better suited to investigate how the distinct experiences of people with epilepsy are reflected in metaphor use and construction of illness identities more broadly. Such narratives of people with epilepsy may be able to highlight when metaphors are (or are not) used in expression of the illness experiences and identities.

3.3 Epistemological Assumptions

I approached this research from an interpretivist paradigm, with the use of both metaphor analysis and narrative analysis. Interpretivism emphasizes the meaning conferred on people's actions and participation in social and cultural life, as interpreted by both the participants and by the researcher (Willis, 2007). Interpretivism insists that any attempt to understand the reality of a phenomenon is subject to the different perceptions and interpretations of each individual, whether participant or researcher (Schwandt, 2000; Sontag, 1989). This perspective aligns with social constructionism, in which there might be infinite interpretations of the same event depending on the context (Crotty, 1998). Each of these interpretations might produce different realities, none of which is the one "true" construct of reality sought by positivist researchers (Crotty, 1998). Willis (2007) asserts that there may exist an intrapsychic reality; however, any reality is a matter of interpretation and there exist no universal truths. Crossley (2000, 2003) identifies a language-based social-constructionist approach to the study of self and identities in her model of narrative psychology, in which she initially adopts the critical realist assumption that one "true" reality

does exist for each participant, arguing that this enables a more useful dissemination of results for clinical settings (Crossley, 2000, 2003). While considering the clinical applicability of results is a possibility for future research, my goals in this study align more closely with Crossley's later stance in which she acknowledges and adopts a social constructionist framework. Within this framework, there exist multiple interpretations of "self" based on the language each individual relies upon to communicate, tell stories, and ultimately make meaning of experiences (Crossley, 2011).

In line with the social constructionist framework, I attempted to understand individual experiences as structured by cultural interactions (Willis, 2007). A fuller understanding of how an individual experiences an action or event requires consideration of her or his context, as there is a distinct interplay between the individual and her or his surroundings (Burr, 1995). This is especially so with the heterogeneous experiences of epilepsy in different cultural domains, where individuals may react differently to their experiences as a consequence of the different circumstances that might exist (e.g., type of epilepsy, physician and family treatment, awareness of cultural or historical beliefs). This research involved the presentation of participants' experiences, as they perceived them, as communicated in my interactions with them, and as interpreted by myself. As such, I am presenting the interpretations that I have made, and am not presenting a solitary truth that exists regarding the lives and experiences of these individuals. The meanings that were derived from the narratives collected were co-constructed; that is, they result from the interactions that I had with the participants as well as with their narratives (Burr, 1995). This meaning-making process was inevitably impacted by the participants' experiences with and perceptions of epilepsy, by the shared participant-researcher experience of these narratives, and by my interpretations of the perceptions expressed by the participants. As it is understood that the co-construction of meaning is impacted by the assumptions, personal beliefs, and values of

researchers, it was necessary for me to identify and revisit my beliefs on epilepsy, as well as to question the roles that my beliefs played in my interpretations of the narratives. It was also necessary for me to acknowledge and gain familiarity with the historical and cultural factors surrounding epilepsy, particularly the language surrounding this experience, in order to better explore the social circumstances in which the meanings were derived (Burr, 1995).

One aspect of the social constructionist epistemology that makes it particularly suited to the study is the way in which language is perceived as social action (Burr, 1995). This emphasis on language and symbolism in the social construction of participants' narratives allowed me to focus on specific metaphors and experiences that I interpreted as most salient in their epilepsy narratives (Gergen, 2015). Lieblich and colleagues (1998) emphasize that a constructionist position enables researchers to observe the way in which individuals construct self-image, through use of language as a resource available in interpersonal interactions and cultural concepts. As the focus of this research was on participants' metaphor use to convey experiences and labels that constitute their identities, investigation based on social constructionism was felt to appropriately address the research questions.

3.4 Metaphor and Narrative Analysis

The primary aim of this study was to gain an understanding of the subjective experience of epilepsy as conveyed through metaphor. A secondary aim was to gain an understanding of the use of metaphors in how they may facilitate or impact the telling of different aspects of epilepsy narratives. The findings are meant to contribute, more broadly, to an awareness and attention to language and the ways in which it is used in epilepsy narratives. As the analysis aimed to identify not only isolated metaphors, but also their possible origins and use in the expression of identities, they were analyzed within the narrative context so that contextualized — rather than more

generalized — meanings can be considered. Before proceeding, I would like to discuss my use of “narrative” and “narrative analysis,” given that definitions of “narrative” range widely. I tend to prefer a broader definition that includes, for example, the narratives that a simple command such as “Stop!” might contain or elicit, or the narrative that a song (for example, Joy Division’s “She’s Lost Control” including the lyrical and performance-based significance) might offer. In my thesis, I refer to participants’ written and oral narratives, as well as to their narratives as wholes composed of narrative units. I occasionally use the terms “narrative” and “story” synonymously, following the participants’ conventions to speak of their contributions (whether oral or written) as their “stories.”² But how do we study narrative?

Polkinghorne (1995) has identified two distinct types of narrative inquiry. The first, *analysis of narrative*, involves collecting stories as a source of data and analyzing them within a set methodological approach, such as phenomenology or ethnography, with the goal of identifying themes or categories. The second form of narrative inquiry, *narrative analysis*, involves integrating and interpreting multiple data sources, such as oral narratives and field notes, to create an explanatory narrative (Polkinghorne, 1995). I carried out narrative analysis according to Polkinghorne’s (1995) definition, with the goal of re-constructing composite narratives that demonstrate my findings. I did, however, encounter metaphor themes and narratives that surfaced repeatedly in my analyses, and chose to address these in the final *Analysis* (Chapter 9) and *Conclusion* (Chapter 10), in which I consider areas of overlap amongst the narratives.

3.4.1 Narrative analysis and narrative medicine. My review of narratives was guided by Charon’s (2006) “close reading,” a central term out of literary studies, which provides a guideline to reading medical narratives as a way to discover important aspects of the teller’s

² I may also use the term “text” when I refer to the participants’ written contributions or the transcripts of their interviews with me.

experience. In line with Riessman's (1993, 2008) broader perspectives on narrative analysis, Charon presents a complementary model that helps sharpen one's attention to aspects of language used specifically within the context of narrative medicine. As this study is geared towards an understanding of language and narratives as they present in the fields of health and social sciences, this approach felt particularly helpful. "Close reading" consists of a detailed interpretation of a text with emphasis on prioritized "topics," Charon's term for what would be considered "themes" in social science's "thematic analysis," and how such topics are prioritized through specific structural elements such as individual words, syntax, and the ordering of sentences and ideas, as done in "structural analysis" (Charon, 2006; Riessman, 2008). A concept such as "close reading" is in line with that of the hermeneutic circle, which alludes to the notion that one cannot fully understand part of a narrative until the whole is understood, and that the whole cannot be understood without an understanding of each part (Harmon & Holman, 2009). Thus, one's interpretations and understanding of narrative elements, as well as the narrative as a whole, are constantly influencing each other. Changes in perception of the narrative and the meanings made are inevitable, and thus the narratives were analyzed through a process of reading, personal reflection, notetaking, and re-reading.

Thematic narrative analysis is traditionally understood as a focus on content, the *what* that is said or written, traditionally with little consideration of aspects such as conversational or contextual factors (Riessman, 2008). While my interest in metaphor focuses on *how* a narrative is communicated, there is nonetheless an interest in the *what*, alternatively considered the themes of the language being used (Charon, 2006). Thematic narrative analysis has frequently been used in the chronic illness research community, and in research on epilepsy narratives more specifically, to identify and list themes, or to represent them using narrative reconstructions that illustrate the

process of meaning-making for individuals living with illness (Riessman, 2008). My interest in integrating a thematic analysis approach with the structural focus of close reading is in an attempt to illustrate which aspects of the epilepsy experience metaphor are used to describe (i.e., the target domains), as well as what meaning-making or understandings use of this language provides.

The first component of Charon's "close reading" that received the bulk of my attention is the "frame" of a narrative. The frame refers to how narrators position their stories by drawing borders around them; attention was paid not only to what borders frame the stories but also to how these borders are drawn. In essence, my concern was how a story is contextualized: by the reader, in history, in society. This included striving to understand and maintain an awareness of the narrative goals, which are dependent on the narrator's awareness of who will be reading (i.e., their target audience), what assumptions are made (both by the narrator and the reader), and what details may have been left out either consciously or based on assumptions. Analysis of the frame is a mostly "language-based structural analysis," to use Riessman's terms (1993). Charon (2006) suggests that this structural analysis should focus on the way that larger portions are structured by narrator positions, as well as smaller linguistic components such as allusion (i.e., intertextual conversations), diction (i.e., choice of words and writing style), and finally, metaphor. Charon (2006) defines metaphor as: "images that crystallize meaning through a fresh juxtaposition or an enduring governing image that runs through or coheres a work" (p. 118). Metaphors, as well as other forms of figurative language, provide meaning beyond the words on the page. Of particular significance is the fact that metaphor can serve the two roles that we are seeking to investigate: both as separate strategies that compose meaning, as well as references to the overarching themes in a narrative (Charon, 2006; Crossley, 2000; Teucher, 2000, 2003). For example, in Chapter 4, a participant refers to seizures as experiences in "shifting energy," a description that informs a

primary narrative theme and identity as one who practices Eastern medicine and “manages energy,” so as to provide perceived control over her own health and the health of others.

The second component of close reading is that of “time,” including the way in which the individual positions both themselves and their illness in relation to the “present” in which the story is told. While a narrative most often involves a chronologically-told story, the sequence in which events are told and the emphasis placed on certain events are of central importance. The experience of illness as an interruption or as intrusive to everyday life is commonly described in narratives of chronic illness (Becker, 1997; Charmaz, 1991; Kirmayer, 2000). Narrative analysis is particularly useful in this regard as it is able to identify, based on the sequence of events described, the ways in which individuals position their illness and their own self in time (Frank, 1995; Good, 1994). Numerous researchers have emphasized the way in which time can provide insight into the illness experiences, for example through verb tense, temporal dislocation or velocity, or the narrative time of “before” and “after” illness commencement and diagnosis (Charon, 2006; Teucher, 2000). What made time of particular interest in this study was the relatively recent appearance of published epilepsy narratives in the past decade in which individuals reflect retrospectively on an illness that they feel they have “overcome” through surgical control. These narratives introduce a new narrative style relative to the epilepsy narrative studies carried out in the past (Good & del Vecchio Good, 1994; Scambler, 1989; Scambler & Hopkins, 1990; Schneider & Conrad, 1983), and thus offered the possibility that the language and narrative form encountered could present differently than sociologists had previously documented. A focus on this element in particular is presented in Chapter 6 and later in a comparison across participants in Chapter 9.

The “plot” of the narrative is the third component addressed by Charon’s (2006) close reading and has received much focus in narrative analysis, often as in the identification of genres

(Riessman, 1990, 1993; Frank, 1995). Plot is said to be inseparable from both a narrative's form (as this includes the way in which events are presented, the *how*) and its temporality (as the events, the *what*, reported are chronologically related). In line with a social constructionist stance, a biomedical narrative's plot would be considered a collaborative effort between the patient and physician, with the goal of discovering a diagnosis. In contrast with a biomedical narrative, I was not collecting or co-constructing narratives with an explicit desired outcome, such as a diagnostic outcome, and thus did not make the assumption of plot for the narratives as a whole, let alone the narrative segments of which they were constructed. Frank (1995, 2010) has identified narrative types that may present at different times in the evolution of individuals' conceptualizations of illness; these are considered as general culturally-available storylines that may be presented alternatively or may underlie the "plots" of individual narratives (Mattingly & Garro, 2000). Narrative types were considered within and between individuals, in part because they appeared to tie largely to the different types of metaphor used at different times in the evolution of illness identity. That is, both the metaphors used and the way in which they were introduced appeared to evolve together over the course of individuals' own perceptions of epilepsy and self.

A unique and oft-neglected aspect of close reading is "desire," in which readers are asked to reflect inward and consider their personal relationships with and interest in the narrative (Charon, 2006; Teucher, 2000). Charon (2006) proposes that one's physical experience of a narrative, such as excitement or exertion, are necessary to attempt to make meaning of another's communication of their corporeal reality. For this aspect, it was helpful to return to field notes from the interview stage and to re-listen to the interviews in order to recall the way that individuals conveyed their narratives and how I had reacted both in the moment and upon reflection. I will next discuss the process in which I gathered data for my analysis, including recruitment, participant interactions, narrative collection, as well as describe how the analytic

process unfolded.

3.5 Recruitment Process

Prior to recruitment, my study received ethics approval by the Behavioral Research Ethics Board at the University of Saskatchewan. I initially intended for my main source of sampling to be through posters placed on the University of Saskatchewan campus boards, on the University Hospital boards, and on the information board for Epilepsy Saskatoon, which serves as the sole community-based epilepsy resource for the province. With minimal medical specialist or community resources available to the epilepsy population, recruitment occurred in a province that is currently not well-equipped to address the needs of people with epilepsy. A criticism of previous studies assessing individuals' experiences with epilepsy was that the recruitment of populations from major treatment centres did not reflect the "typical" lived experience of being diagnosed or treated (MacLoed & Austin, 2003). It was thus anticipated that the participants recruited may better reflect a diversity of experiences more relevant to the majority, potentially contributing to the relevance of results to the general population.

Through consultation with the Executive Director for Epilepsy Saskatoon and a neurologist at the University Hospital's Epilepsy Program, it was determined that my best chance at recruitment would likely be through reaching individuals in a non-confrontational but active role. The Executive Director for Epilepsy Saskatoon suggested that individuals may be eager to talk but hesitant to respond to more passive recruitment, such as via newsletter. The neurologist with whom I consulted had also observed patients who did not respond to recruitment posters for his own studies, but he found that they were more engaged when directly asked about participation in appointments. When I approached Epilepsy Saskatoon about my study, I was invited to speak and distribute recruitment materials at the Annual General Meeting (see Appendix D & E). This generated interest from several members, and resulted in recruitment of

six (6) participants initially. One (1) participant later declined based on deterioration in his health, and two (2) additional participants later decided that they were not interested in sharing their experiences with epilepsy. A total of three (3) participants were therefore recruited from this method. One participant later referred her father as an additional one (1) participant; however, his narratives were used as accessory information for her narratives rather than as an independent source. Two (2) additional participants were recruited through word-of-mouth; these participants had epilepsy but were not involved with Epilepsy Saskatoon.

3.6 Participants

For the purpose of the study, five (5) adults who living with epilepsy were included as participants in individual comprehensive case studies. A sixth participant did not meet the study criteria but was still interviewed and his input considered as an additional resource in my reconstruction of his daughter's narratives, as she was one of the five participants. Participants had to be willing to share their personal experiences with epilepsy and feel comfortable taking part in audio-recorded interviews. These five individuals met broad inclusion criteria that aimed to consider a diversity in descriptions of epilepsy experiences and identities. First, as the study focused on experiences with epilepsy diagnosis, treatment, and daily life, I sought individuals who were diagnosed at least one year prior to the collection of narratives. Second, individuals had to have been diagnosed with epilepsy following standard criteria, i.e., that individuals had to have experienced more than one unprovoked seizure (Berg et al., 2010). Because some children naturally outgrow their seizure disorder, a further requirement was that individuals either continued to experience seizures (i.e., at least one seizure in the past year) or were on medication that was managing their epilepsy. The sixth participant, mentioned above, was excluded from a full case study as he had not experienced seizures or had not been medicated since his teenage

years, approximately 50 years prior to my interactions with him. Third, I included some individuals whose seizures were not under control for two reasons: 1) intractable epilepsy is significantly correlated with greater psychosocial difficulties; and 2) improvements in biomedical treatment may well lead to different experiences and perceptions of epilepsy (Téllez-Zenteno et al., 2004).

3.7 Data Collection

The research utilized a three-step process to identify metaphors and narrative themes expressed in reference to epilepsy. As discussed, the first step involved a review of published life writing, related research, and medical literature, in order to map out a range of current conceptualizations of epilepsy. Next, data for metaphor and narrative analysis were generated through the use of written, then oral, narratives.

The collection and qualitative analysis of invited written narratives from people with epilepsy served to better understand their experiences and perceptions of epilepsy, as well as to identify the diversity of metaphors used. My initial encounters with participants involved brief discussions of my study and distribution of my *Letter of Invitation* (Appendix E) to to take part in the study. For those participants who expressed interest in participating, I then met with them in person to discuss what the process would entail and answer any questions they had. These meetings were generally informal and brief, and took place at coffee shops, on campus, and at Epilepsy Saskatoon. Upon hearing more about the project and agreeing to participate, I reviewed the *Consent Form* (Appendix F) with participants. Next, I arranged for them to prepare their written narratives and encouraged them to use their preferred method (i.e., handwritten or typed) with a rather broad request: “Tell me about your experiences with epilepsy.” These individuals were not directed to list metaphors or specific stories, so as to minimally impact the way in which

they may or may not use metaphor or other linguistic resources. I asked participants to take the time they needed and to contact me if and when they were ready to share their written narrative. All of those who had agreed to write chose to share their written narratives with me, and all but the sixth participant, whose narrative I do not explore in detail, chose to type their story and email it to me.

Once I had received an email with a written narrative, I corresponded with participants over the phone or over email to arrange a time and location in which we could further discuss their written narratives and their experiences with epilepsy in person. The details of these meetings are discussed in the introductions to each participant, and these took place in varied locations (e.g., their homes, their workplaces, an interview room on campus). Prior to meeting with the individuals in person, I reviewed the written narratives, which involved the identification of elements of interest (e.g., specific metaphors, narrative themes), as well as note-taking for later review and for follow-up items to note on the general *Interview Guide* (Appendix C). This guide was used as a reference for key aspects of the epilepsy experience that were anticipated to be discussed (e.g., seizures, medication, etc.). Every attempt was made to use this guide minimally and, more often, I used this guide to remind myself of unique terms or areas of focus in a participant's written narrative, with the intent of further exploring information that I heard repeated in the oral narrative, or information that I felt needed clarification.

The oral narratives provided an opportunity to gain a richer understanding of how these individuals made meaning of their illness. Upon meeting with each individual in the interview setting, I reviewed the consent form again and offered them the opportunity to provide a pseudonym to maintain anonymity. All five individuals initially indicated that they would be comfortable with me using their full names, but agreed to the use of pseudonyms, and only one participant offered an alternative name (i.e., Captain Epilepsy, who we will hear from in Chapter

5). After reviewing consent and pseudonyms, I then began recording our conversations. To begin, individuals were again asked to: “Tell me about your experiences with epilepsy,” allowing them to direct the oral narrative but nonetheless acknowledging my role as a participant in the conversation and co-construction. Only at the end of our conversations were individuals asked to identify any metaphors that they felt described their personal experiences with epilepsy, as well as metaphors they might have encountered in healthcare settings, interpersonal interactions, and societal or historical perceptions of which they were aware. These metaphors were used to further inform the concepts of selves, illness, and the ways in which these linguistic resources might have impacted construction of narratives. It was anticipated that follow-up conversations or interviews may be needed to clarify material or in case not enough information was provided. Indeed, I did make note of and research, additional materials that participants referred to either during or after our formal interview session.

Following my interview session with each individual, I made notes regarding our interactions, particularly any gestures and other non-verbal communication that I had observed and that I felt might help inform transcription and reflection upon the oral narrative transcripts. I later transcribed the oral narratives, listening to them several times and at a slowed pace to make every effort to capture the entirety of our conversations. As will be observed, many conversations involved participants recalling conversations with others, and I revisited my transcriptions while listening in an attempt to capture the intonation used. Over the course of repeated listening, I produced oral transcripts that were numbered by line, and I used these line numbers throughout the analytic process, to facilitate my ability to extract and consider words, sentences, and/or narrative segments separately, while also enabling me to return and consider these extracts in the context of the entire narrative. Once the oral narratives were transcribed, I dealt with the material primarily as written text.

3.8 Sources of Data

The sources of data consist of the written narratives, oral narrative transcripts, and supplemental materials including additional conversations (in-person, phone, and email), poems, articles, books, and *YouTube* videos that participants referred to during our interactions. Informal note-taking occurred throughout collection of the narratives, serving as another supplemental data source that I referred to frequently. As mentioned, the participants were asked to reflect upon and consent to the analysis of their narratives (Appendix F). In my dissemination, all participant quotes presented are from the oral narrative transcripts unless otherwise noted as being from the written narrative.

3.9 Data Analysis

Data analysis took place in stages incorporating the close reading strategies previously outlined from Charon (2006). The methodology integrated narrative analysis as informed by Riessman (2008) and Charon (2006), with analysis of those metaphors encountered in accordance with the prior discussion on metaphor (Lakoff and Johnson; 1980; Ritchie, 2006; Kirmayer, 1992, 2004). These offered pragmatic and complementary methods with which to approach the research questions, providing structure to the necessarily “messy” process of narrative analysis. Data were coded primarily through note-taking on printed copies of the narratives, with earlier iterations coded through highlighting and comments on *Microsoft Word* documents and recording in qualitative software (Dedoose 6.2.21). As stated, some of the primary metaphor domains or targets were identified in advance based on research questions (e.g., metaphors in reference to seizures, epilepsy, treatments, etc.) while other metaphor sources and targets emerged through the coding process (e.g., metaphors in reference to perceived stigma, perceived control, etc.). Given the nature of the research and the presentation of the data as re-constructed case studies, there

were certain data sets that were unique to the individual narratives and will be discussed in the re-constructed individual narratives to which they applied. A comparison of data sets across individuals will be reviewed in the Chapter 9.

While the ability to visualize data sets throughout computerized coding was helpful, I found myself more frequently returning to paper copies that were colour-coded for data sets and contained detailed notes, as these made the stories more tangible and contextualized. For each narrative, I created lists of metaphors and text extracts, followed by visual layouts (e.g., tables) of larger themes to which these metaphors and extracts might belong. This was a time-consuming process in which I frequently moved from visual layout to list, or visual layout to individual narratives, until I had established a data set that I felt reasonably reflected a metaphor or an extract's role in my interpretation of a participant's narrative. This involved the addition and removal of certain data sets as I came to identify overarching themes. I also found myself moving between narrative re-constructions and data sets to ensure that I was interpreting metaphors in a way that best represented my understanding of a narrator's original presentation of the material.

The largest units of analysis were the entire written and oral narratives provided by each individual (Riessman, 2008). After several readings in order to familiarize myself and reflect on the overall narratives, made up of the written narratives and oral narrative transcripts, each narrative was analyzed for the "narrative segments" that made up the narratives. Narratives were analyzed for the metaphor targets or major epilepsy-related events (e.g., seizures, medications, etc.), as well as the metaphor sources or themes (e.g., electricity, machine, etc.) that they contributed, as well as the role that these elements played in framing the individuals' narratives overall (Charon, 2006; Riessman, 2008). Attention was paid to the connections made between both the linguistic and thematic components of each narrative segment (Riessman, 1993, 2008).

Given my interest in metaphors, I carried out multiple readings to address the role of

metaphors in the narrative. My first reading for metaphor specifically involved coding every metaphor, whether an individual term, narrative segment, or overarching concept. Based on readings of published narratives and prior epilepsy narrative research, as well as my first encounters with the narratives (prior conversations, interview notes, and initial readings), I anticipated and grouped four broad groups of metaphor targets: those in reference to seizures, epilepsy, medicine (e.g., physicians, diagnosis, treatments) and social circumstances (e.g., family relationships, social and cultural interactions). I returned for my second metaphor reading, re-coded what metaphors were used, and identified whether they were used in reference to one of the four broad groupings I had anticipated, or whether they were used to refer to newly emerging concepts. As I became better acquainted with each narrative, I coded additional aspects of the illness experience that different metaphors were being used to convey. This enabled me to identify areas of overlap between narratives, as well as to highlight more idiosyncratic uses of metaphor. Given that metaphors frequently and necessarily shaped the narratives told, as well as narratives influencing the way in which metaphors were used, I frequently shifted back and forth between coding for metaphor specifically and coding for narrative topics (or themes) overall. Metaphor analysis was used to examine not only which metaphors were used, but also how they were used within the narrative segments and narratives as a whole (Charon, 2006). That is, metaphors sometimes stood alone, played the role of “narrative linkages” which connect separate stories or sections of a narrative, or acted as centralizing metaphors that reflect overarching perspectives in the narrative (Charon, 2006; Denzin & Lincoln, 2000). With an interest in the ways in which these components contribute to communication and identity reconstruction, there was particular focus placed on how the narrative segments were conveyed, and how associations (or narrative linkages) were drawn between them (Denzin & Lincoln, 2000).

Field notes served as a valuable tool to record observations and reflect upon trends seen

both within and between the narratives (Riessman, 1990, 2008). Each individual's narrative was revisited and used to consider how these narratives have come to portray one or multiple illness identities. Finally, all of the narratives were compared and contrasted to identify similarities and differences in the ways in which individuals conceptualize and express their life experiences with illness through metaphor, and the resulting illness narratives that emerge. As each new narrative was considered and coded, a table was used to summarize targets of metaphor use (e.g., seizures, treatment), overarching themes, whether each target or theme presented for each individual and, if so, what metaphor(s) were used. Frequent updates and alterations were made to this list of themes as narrative was analyzed, re-constructed and re-visited.

An additional type of "field note" that I initially used quite unintentionally was similar to Charon's (2006) suggested narrative medicine approach of "parallel charting." In order to have her medical students focus on patient experiences beyond what goes into the medical chart, Charon (2006) asked that for each patient, her students write not only in their medical chart, but also a personal reflection as a means "to focus on what their patients had to endure in the course of being ill" (p. 173). There are two reasons why this "parallel chart" concept was useful to me. First of all, while I never asked participants for medical information such as diagnostic labels or treatments, each individual did use these terms in describing their experience with epilepsy. Second of all, because I have worked in a clinical role with epilepsy patients, I had become familiar with carrying out clinical interviews in which patient histories were written in a medical model format for the purpose of case summary and presentation to a team of physicians at rounds. While I had already taken field notes, interviewed the participants, and was writing up an analysis of their narratives, their tendency was to present me with an illness narrative that was heavy on medical jargon, and my familiarity was with a format of case presentation that was also heavy on medical jargon. When I returned to my data, I wrote introductory summaries from this

medical approach, including the basic details of participant symptom presentation, diagnostic labels, and medical conceptualization (see Appendix G). While Charon's students utilize parallel charting to shift their focus from the biomedical to the individualized illness experience, my parallel charts served a different purpose: they allowed me to "parallel chart" my biomedical conceptualizations and consider how these may or may not relate to the individualized illness experience and conceptualizations I was seeking to examine. This exercise gave me some fantastic insight into how these individuals had come to use medical jargon, how I myself had come to interpret individuals' presentations this way, and the power that this type of terminology and presentation held over the individual illness narratives and terminology that I was seeking to explore (Charon, 2006; Gergen, 2015). These summaries served as an interesting tool and a helpful reminder that I had to again be very careful in acknowledging my own assumptions.

The "coda" is an element of Charon's "close reading" that is identified as falling at the end of a narrative and providing concluding remarks and reflections. In the doctor-patient relationship, it can be demonstrated that one has paid attention to an oral narrative by repeating the information that has been heard (Charon, 2006). Such an act promotes both the witnessing of patient stories and a healing process in the narrative effort to make meaning of the illness and reconstruct identities (Frank, 2010). In my study, I invited my participants to communicate their narratives in writing prior to sharing their oral narrative, so as to provide both them and myself the opportunity to reflect upon what they had shared and to increase the likelihood that, by integrating their own terminology, they would feel heard. Many of the written and oral narratives involved concluding statements that were apologetic and sometimes self-deprecating (for example, "*I hope this was useful.*" or "*Soapbox time. In need of an editor.*") These communicated to me the self-identities of individuals who might have come to believe that their narratives were not worth hearing, whether based on self-perception or something that they had

perceived through direct or indirect past communications with others. These minor comments in fact offered a fruitful area to discuss, as well as an opportunity to validate the importance of these stories.

3.10 Validity

In a model aimed at ensuring validity of qualitative research findings, Thorne (2008) posits four criteria for ensuring rigor and credibility. First, *epistemological integrity* requires that the researcher's methodological approach be consistent with the stated stance on ontology and epistemology. Second, *analytic logic* demands that, in line with epistemological consistency, there is evident transparency in the decisions made from project development through analysis. Third, *representative credibility* requires a constant awareness of the multiple perspectives presented in regards to a particular phenomenon, as well as contextualized representation of the diverse perceptions of the phenomenon as expressed in the narratives. This is of particular importance when considering the context-dependent nature of findings, such as the written and conversation-based narratives collected, as these may or may not relate to other populations and practice (Glaser & Strauss, 1966; as cited in Thorne, 2008, p.193). Finally, *interpretive authority* involves ensuring that the findings presented are trustworthy and reveal results that are not simply a reflection of the researcher's biases, best addressed by having myself as researcher identify possible biases, by reviewing and re-visiting results, and by having participants open to provide comments after transcript collection (Paterson, 1994; as cited in Thorne, 2008). Under this criterion one could position triangulation, which involves convergence of multiple data sources (e.g., prior theories, researcher analysis, written and oral transcripts, field notes). Thorne (2008) suggests that such criteria ensure — both for the researcher, and for the audience who will be reviewing the research — that a reliable system of analysis and presentation have led to valid

findings. So as to address the element of interpretive authority and to consider my role as both a researcher and a participant in conversations, I reviewed my background and the multiple ways in which it may have impacted my analytic process.

3.11 Researcher Background

There are many ways in which my personal background may have affected the way in which I carried out and interpreted the research. For one, I came from a research and training background that relies heavily on quantitative and biomedical methods, as well as quantitative language. This background encouraged me to focus on research for its statistical value, but this was not the goal for my current study. My background challenged me continuously as I tried not to focus on the statistical value, and it was difficult for me to adjust to research that does not involve quantitative analysis. I repeatedly attempted to develop “quantifiable” analyses, but eventually came to accept that the increased frequency of a specific metaphor or story did not make it more research-relevant; on the contrary, there were often metaphors that were used only once but that seemed to carry a more powerful role in understanding an individual’s experience.

My clinical training in medical settings may also have biased me to interpret illness from the perspective of the “medical model.” I trained in settings focused on neuropsychological illness and conditions, including an epilepsy clinic. When I stepped back to consider these experiences as they influenced my research, I found it both fascinating and motivating to reflect on the exchanges between patients and physicians. It struck me how terms such as “zombie,” “cloudy,” and “out of it” were part of a mutual patient-physician vocabulary. These were introduced into clinical interviews by both patients and physicians alike and were treated as pseudo-medical terms that had clearly been crafted to capture experiences that medical terms could not. My interest in this unique — yet shared — vocabulary grew both for the sake of

professional practice, as well as in the research forum.

My clinical neuropsychology training also taught me to focus more frequently on communicating with colleagues using accurate diagnostic labels and quantifiable health-related components of illness, more so than focusing on individual narratives and linguistics as a means of understanding patients. In an attempt to consider this factor, I repeatedly turned to researchers within the medical field who had experienced limitations due to their training in the medical model. As an ethicist working in hospital settings, Zaner (1988, 1993) provided helpful reflections based on his experience in making sense of patient-physician interactions, for himself as well as the main parties involved. Frank, a medical sociologist, and Kleinman, a medical anthropologist, have both reflected on the limitations of the medical model in capturing illness narratives in their earlier publications (Frank, 1995; Kleinman, 1988). Notably, both individuals identified their research as stemming from their experiences as patients within a medical system, patients who became motivated to research and teach alternate perspectives on what they identified as the traditional medical model. Finally, Charon (2006) was an invaluable source for considering how to work in a way that was mindful of the medical model as a contextual factor. Charon's teaching practice of having students write "parallel charts" in which they write diary-style entries regarding their interactions with a patient, alongside the medical charts that will be admitted into hospital records, helped me to capture my early conceptualizations of participants, as I summarized medical information that had been shared in their narratives (Appendix G). It was in consultation with my research supervisor that I became aware of these different interpretations and the benefit of reflecting on these different interpretations in my narrative conceptualizations.

A final factor that both prompted and affected my research has been my own experience with epilepsy. Initially, this was a motivation to gain and contribute to a greater understanding of

the illness that has been a part of my life. In completing a Master's in behavioural neuroscience of a rodent model of epilepsy, I became aware of both the research community and patient community surrounding epilepsy. My volunteer work with community members who were living with epilepsy made me increasingly aware of the significant psychosocial consequences that this illness had on a population that appeared relatively underserved. I base this statement on my attendance as a researcher at the American Epilepsy Society (AES) and Canadian League Against Epilepsy (CLAE) conferences, in which research tended to focus on diagnostics and medical treatment, with a handful of individuals representing the psychosocial field. In contrast, my attendance as a researcher and community member at the Canadian Epilepsy Alliance (CEA) conference made me aware of community groups across the country that were struggling to maintain the funding needed to provide psychosocial support to their members. Throughout my academic and community experiences, I have been involved in trying to gain an understanding of the causes, consequences, and multilayered treatment strategies involved in epilepsy research. While my personal experience may impact my interpretations, it also stands to benefit the research as I may be more aware of the unique challenges and communication strategies facing these participants. The story of each individual is a distinct narrative and was interpreted as such. It was nonetheless crucial to maintain an awareness of my own perspective on experiences with epilepsy, including reflections, repeated note-taking and conversations with my supervisor and colleagues to gain perspective on the vocabulary with which I was already most familiar.

3.12 Significance

The goal of my research is to provide an awareness of metaphor use in epilepsy discourse, reflecting how individuals make sense of their experience with epilepsy, as well as how this meaning-making process may be impacted by perceptions of medical and social beliefs. The

research aims to inform research and health care communities regarding individual perceptions of epilepsy as conveyed through language, specifically metaphor, and may lead to an understanding of those communication strategies and specific language that may best support positive identity development in people with epilepsy. Understanding the use of metaphor in individuals' communication of epilepsy experiences and associated identity re-constructions is useful in highlighting the crucial role of language awareness when providing psychosocial support to this population.

3.13 Introduction to the Analysis: Reclaiming Control

While control is a prevalent focus in much illness and epilepsy narrative research (Bruner, 1990; Charmaz, 1991; Kirmayer, 1993; Kleinman, 1988; Schneider & Conrad, 1983), I returned and explored this concept further after speaking with participants who stated verbatim that “loss of control” was a primary component of the seizure and epilepsy experiences, and in also noting that participants relied on multiple metaphors that appeared to serve a role in their meaning making experience around losing and reclaiming control. I have focused on control in the *Literature Review* and have integrated research on this topic as it applies in the *Analysis* chapters, as a means of illustrating the co-construction of diverse concepts of control depicted in the narratives and further interpreted by myself. In my narrative reconstructions, I attempted to reflect the diversity in the uses of control conceptualizations by quoting and referencing it both literally (e.g., a physical “loss of control” during a seizure) and figuratively (e.g., “losing control of my world,” “epilepsy took over”); in the figurative instances, I reference “perceived control” as per the research previously discussed by Velissaris and colleagues (Velissaris et al., 2007, 2012) to reflect the ways in which individuals proceeded to interpret their relationship with perceptions of control of “lost” and “reclaimed.” The finding that epileptic seizure metaphors

emphasize a perception of externalized control (Plug et al., 2009a; Schwabe et al., 2007, 2008), along with the finding that these control-focused metaphors connect to illness coping strategies (Monzoni & Reuber, 2009), powerfully illustrates the importance of perceived control in the epilepsy experience. I will revisit research on control in epilepsy as I narrow my focus in the *Conclusion* sections, as a means to consider my findings from individual narratives and narrative comparisons in the context of the current research. While the utility of seizure metaphor typologies has been demonstrated to be useful in epilepsy diagnostic practices (Plug et al., 2009a, 2009c), observing seizure- and epilepsy-specific metaphors could also prove useful in improving treatment practices. Ultimately, I note that attending to patient metaphor use in personal narratives could lead to improved communication and quality of care for people with epilepsy, particularly around the perception of control in both the seizure- and epilepsy-experience.

3.13.1 Reclaiming control: Individual concepts. In my study of five narratives, I focused on those target domains of perceived control that played the largest role in metaphor use and narrative use. While I tended to prioritize the metaphor domain(s) that each participant seemed to present as central to their epilepsy experience, there did exist overlap and these comparisons between narratives will be discussed in Chapter 9. Each narrative is re-constructed and presented in a way that I felt best represented the participant's style of narrative presentation, as well as what I perceived as the focus of their communication. Despite differences in narrative re-construction, each epilepsy narrative involved a narrative turn in which the individual expressed a loss of control. As this was frequently the focus of the first seizure, I have included the "seizure narrative(s)" for each participant as a platform from which to explore the progression of her or his experience. Participants appeared to conceptualize the loss of control and attempted

to reclaim control somewhat differently, and often determined the different metaphor domain(s) upon which they focused.

While they all spoke of similar themes and stages in the epilepsy narrative trajectory (e.g., first seizure, diagnosis, treatment, social identity, etc.), the narrative identities that I interpreted as being depicted differed based on the participants' communication of what main concept(s) conveyed control of their epilepsy experience. In Chapter 4, Hannah describes a transient role in her seizure and epilepsy experiences; her position on the edge of the mind-body, victim-healer, and the witness-witnessed roles enables her to shift between roles that provide her the best opportunity to retain control of her health and identity. In Chapter 5, Clark illustrates a traditional divide between the disease-illness experiences. He illustrates his mastery of mechanical metaphors in biomedical interactions surrounding epilepsy, but appears to turn to social and spiritual metaphors to convey the majority of his epilepsy experience, including his identity as “Captain Epilepsy.” In Chapter 6, Rose characterizes herself as controlling her identity by defining the social boundaries that she has created surrounding the epilepsy experience. She reflects over the aging process and maintains that, despite the shrinking boundaries imposed by her illness and social circumstances, she will always hold control over her medical label. In Chapter 7, Cam portrays himself as an objective observer over time, defining Cam and Epilepsy as separate identities and utilizing those personal and medical labels that control the separation of Epilepsy as external to himself. In Chapter 8, Grace reflects on her control of the physical self, as it relates to her seizures, her ability to dance, and her ability to express herself. Let us now turn to the *Analysis* chapters and consider these primary metaphors within the narratives, as co-constructed by the participants and myself.

CHAPTER FOUR

Hannah: Epilepsy Roles and “In-Betweenness”

4.1 Meet Hannah

Hannah had become aware of my study through a colleague, and we arranged to meet for coffee to discuss what the project entailed. Hannah was a 47-year old mother of two who lived with her husband and children. Hannah appeared very open and aware of her experiences with epilepsy, which began in her teenage years, and she seemed enthusiastic to explore her epilepsy experiences by sharing them with me. She identified epilepsy as something that no longer played a central role in her life, given that she had been diagnosed and treated in her teenage years, yet she still appeared quite mindful of daily strategies that she used to manage her health. Our initial meeting in a coffee shop allowed us to discuss her involvement in the project and to review the consent process.

Shortly after we met, Hannah emailed me a written narrative: “My Epilepsy Journey,” which she explained was a collection of her own thoughts, as well as input that she gathered from her husband, mother, and friends. Her written narrative was a linear chronology of her early seizures and epilepsy experiences, opening with the sentence: “*It began when I was 15 years old.*” At the end of the narrative, Hannah had some draft notes listing each of her “grand mal” seizures and who might have been present for these seizures. A question listed at the end of her narrative was: “*How has it affected me?*” Whether or not this question consciously guided her writing, Hannah described in great detail the increased level of spirituality and awareness of her physical energy that she gained from alternative medicine practices that she used to make sense of and heal from her epilepsy:

I also have been on an on-going healing journey, which I may not have pursued had I not been wanting to heal myself. I have meditated, done yoga, massage, cranialsacral therapy, reiki, energy balancing, and various other techniques. I believe that having epilepsy has taken me down this path of healing; that I may not have been motivated to learn about all these various techniques if not for having epilepsy. (Written narrative)

Hannah's written narrative focused mainly on the impact of her epilepsy on her early identity and peer relationships; however, as seen above, she ended by briefly touching on the role of energy in her "healing journey." Energy and "energy balancing" came to play a much larger role in the conceptualizations and metaphors she used in her oral narrative, with her definitions of energy reportedly based on practices of yoga and reiki. Such practices focus on energy as a "life force," and consider chakras or "energetic channels" or "centres" that must be stabilized to manage seizure occurrence (Ricotti & Delanty, 2006). As will be observed in her narrative reconstruction, Hannah resorts to different conceptualizations of energy but remains focused on the goal of balancing said energy.

When we met again in a University interview room, Hannah was relaxed, invested, and anything but guarded; she invited questions and frequently reflected on her own statements while we talked. She explained that she had invited opinions from family members and friends who may have seen her have a seizure or who had been involved in her epilepsy experience. Her oral narrative focused on the impact of seizures on her life roles as a daughter, friend, wife, mother, and healer. Her defining of these roles appeared to be impacted by two primary conceptualizations of her seizures, both of which indicated attempts to control or "balance" the seizure experience. First, she conceptualized her social identity in the instance of seizure occurrence, describing what it felt like to be "witnessed" having a seizure, as well as what it felt like to "witness" the seizures of others including her sister, who had recently experienced

seizures secondary to encephalitis. Second, she conceptualized her mind-body relationship in the instance of seizure occurrence, prioritizing metaphors related to spirituality and energy in relation to management of her seizures. Hannah's description of her first seizure was very factual, though it contained the central focus of her "epilepsy journey:" struggles for control. These include a struggle for social and identity control between her and others in her life (e.g., parents, peers, doctors), as well as a struggle for physical control between her mind and body. Hannah's could be seen as a quest narrative in which she gains a greater concept of what it means to be healthy in her attempt to gain control over her own illness (Frank, 1995). In this narrative, she uses vocabulary from Western biomedicine, what are often labelled complementary or alternative Eastern medicines, as well social interactions that she associates with her conceptualization of identity.

4.2 The Revolving Door of Epilepsy

Hannah's narrative seemed to be told from an unlikely place; while her narratives were for the most part told retrospectively, she often appeared to locate herself right in the middle of her epilepsy experiences in a seeming attempt to maintain "balance" and control. She thus made it clear that while some resolution had been achieved in accepting her epilepsy, she nonetheless experienced ongoing shifts in her own symptom control, which seemed to impact whether or not epilepsy was a shared aspect of her identity as a whole. Hers was a rich narrative that expanded on a concept put forward by Schneider and Conrad (1980) in the context of revealing one's epilepsy identity: "the closet of epilepsy has a revolving door" (p. 32). Each of the participants identified social contexts in which they chose to disclose or conceal information about their epilepsy, essentially re-entering and re-exiting this "revolving door" into an illness identity; however, Hannah's narrative focused more than any others on these repeated identity shifts and

transitions. In fact, the primary focus of my discussion with Hannah was her transitions, not only between disclosure and concealing her epilepsy, but also her transitions during the seizure experience itself, including physical transitions (i.e., from perceived control to loss of consciousness) and psychosocial transitions (i.e., from one being witnessed having a seizure to a person witnessing and supporting others). Rather than avoid discussion of these conceivably difficult transitions, Hannah sought to explore and discuss the changes and challenges that she had experienced. Multiple terms were used in Hannah's communication of her transitions, and I will explore three categories of metaphor that dominated her written and oral narratives: *witness/witnessed*, *mind-body divisions*, and *victim/healer*. All three of these categories of metaphor were presented as dichotomous elements and involved Hannah positioning herself as on the "edge" and frequently transitioning in between elements as she strived to maintain control.

While Hannah articulated the need for control of her body and physical environment, this need for control is also apparent in her storytelling and social roles (e.g., as mother, daughter, and healer). She demonstrated this control by creating boundaries with her language; defining social and physical experiences with words and stories that she appeared to feel safe with, terms that are her own and thus are under her control. Hannah's narrative is constructed in such a way that she lays out the stakes that constitute her identity, defining the boundaries of what is allowed "in" and what is being kept "out" of her self-identity. She frequently referred to the different levels on which these elements are present, further adding to the framework in which she exists and transitions depending on her needs (Nijhof, 1998). Many of her stories are structured such that she appears to locate herself based on the obstacles she has overcome, the individuals she has supported, and those who benefit from her perceived ability to balance and control her own boundaries.

4.3 Hannah's Social Seizure Narrative: Witnesses

A strong illustrator of Hannah's struggle for control over both her epilepsy and her epilepsy identity can be observed in the way she described the social experience of a seizure. Hannah's narrative relies heavily on the role of the witness. She describes her epilepsy experience involving the role of those who witnessed her seizures, as well as her role as witness to the seizures and illnesses of others. Seizure descriptions from a "witness" are commonly used in biomedical forums as an important source of information for seizure diagnosis and classification, for example: "Epilepsy is a clinical diagnosis based on an individual's account of their symptoms and, crucially, an eye-witness account of events" (Smith, Defalla, & Chadwick, 1999, p. 16). The witness role is also a common theme in epilepsy narratives, as individuals frequently recall elements of their seizure including who observed— or witnessed— the seizure as well as what these individuals observed (Brosh, 2011; Faircloth, 1998a; Nijhof, 1998). When describing their experiences to a neurologist, individuals with epilepsy were noted to identify both the subjective details of their seizure experiences (i.e., as the individual witnessed having the seizure), while also providing objective details as reported by a witness of the experience (Plug et al., 2011; Reuber et al., 2010). As I will show in the following section, Hannah demonstrates narrative slippage in recounting her seizures, particularly those in which she loses consciousness, in that she shifts from the role of "witness" to "witnessed" throughout her narrative in order to create a coherent script of how a seizure occurs (Faircloth, 1998b). This shift between two roles may be an effort to fill in the gaps for when she is not consciously present, so as to create a coherent timeline. It also provides the opportunity to maintain control of the plotline, enabling her to stand in different roles as she narrates the occurrence of a seizure. At times, Hannah appears to use her role as "witness" to negotiate and distance herself from her own seizure experiences, as the one being "witnessed."

4.3.1 First seizure, first witnesses: “I couldn’t control it.” Hannah’s description of her first seizure at age 15 illustrates her attempt to make sense of a loss of physical control. It provides insight into the early dialogue between her mind and her body as she experiences epilepsy, as well as the emphasis placed at this early point on her panic surrounding loss of control:

I mean it’s definitely scary you know because you don’t know what’s happening to your body. I mean I didn’t know what was happening to my body. I just remember that first time when I was going down to pick up this towel and I couldn’t pick it up and I just kept going and, you know, it was just like, you know, this weird experience of I can’t control my body. You know, that was the first time I couldn’t control it. I went down 4 or 5 times and I was trying to stop and I couldn’t and I was just like, “What is going on?” So at first I was like, confusion, not sure, it was scary but I was like, “I don’t know what that was” ... and just trying to like, blow it off, you know? Oh like, “that was, I don’t know what that was but I’m gonna go to school”... cause it happened in the morning.

While told retrospectively, Hannah appears to emphasize her inability to control her body as the most salient element of her first seizure experience. Nonetheless, she describes a desire to dismiss the experience. As with many narratives that depict the role of a witness in the narrative, including many published narratives as well the majority of those considered in this study, the individual may dismiss or minimize the experience of a seizure until it is witnessed (Faircloth, 1998a; Snape, 2015):

And so I went to school and I don’t know, ya I don’t remember if I told [my parents] before I went or not, I think I just went to school and then when I came home that night

for supper was when I was filling up this plate of food and I was just like (demonstrates jerk of her arm)... you know I couldn't control it, and it just flew, you know?

Hannah's written narrative portrays a common diagnostic trajectory, in that many individuals do not seek medical care until their seizure has been witnessed:

My mom was right there watching it all and very upset; my dad and my siblings were at the kitchen table in the other room. Both parents were worried and decided to take me to the hospital right away. (Written narrative)

For safety and diagnostic purposes, the biomedical "witness" role seems an essential one (Smith, Defalla, & Chadwick, 1999). However, it appears that Hannah, as well as many narrators with epilepsy, experience "witnesses" for the social roles that they might play in judging and responding to the seizure behaviour observed. While Hannah's description portrays parents who were understandably concerned about their child's well-being, there exists in this passage and other "witness" passages in Hannah's narratives an element of perceived concern regarding others judging her "normality" based on what is witnessed. For Hannah, this appears to create a role for the "witness" in identifying and even judging "abnormal" behaviour.

4.3.2 Witnessing oneself: "It's my warning sign." Hannah's descriptions of her later myoclonic jerks seemed more simple and straightforward: *"I just jerk."* Her description of her jerks relied on descriptions from a variety of witnesses, including her parents and friends in her early teenage years to current day relationships. Notably, Hannah seemed to identify herself as the primary witness, describing the physical action as one for which she was consciously aware and present. She comfortably described what these jerks entailed (e.g., repetitive hand movements, accidentally dropping objects) and casually re-enacted these motions in the interview. She described her present day jerks as negative primarily in their relationship to the

possible progression into more serious seizure types. Thus, what began as her first experience of an inability to control her body has become a “warning sign” for an even greater loss of control:

Hannah: *I just have once in a while, like, then I can't say how often... I just jerk. Like that (demonstrates jerk of her arm). So sometimes, maybe a couple times a year or a couple times a month but really it varies. I can't remember the last time I had one, like a jerk kind of thing, like that's the only thing where I kind of, "Okay, take a break... take a breath" ... It's my warning sign kind of thing, right?*

Me: *Your warning sign for what?*

Hannah: *For potential sei- for a grand mal or... ya, that it's going to get intensified if I don't stop or slow down.*

Hannah describes her myoclonic jerks as disruptive in her early years but they quickly shift to hold a less central role in her narrative once she began experiencing grand mal seizures. Her later descriptions suggest that she has come to equate the term “seizures” with “grand mal seizures,” making her jerks a more incidental event. This pattern has been observed in epilepsy patients who tend to focus their descriptions on their most severe and most physical seizure type, typically labelled as a “grand mal,” “tonic clonic,” or “generalized” seizure (Plug et al., 2011). When describing her attempt to determine what needed to be included in her narrative, Hannah explained:

... it's not always clear about when you have things or when they're, you know, what, like how many seizures I had or when I had them, like I think I probably had about... 13 or 15 seizures in my life, like grand mal.

She again emphasizes her grand mal seizures as those of relevance when highlighting the toll that her schooling schedule had on her body: *“I think I had like 3 seizures, grand mal seizures over*

that time because it was, ya, it was a rigorous schedule.” Hannah’s different experience with grand mal seizures as opposed to myoclonic jerks is further illustrated when she is asked to describe the appearance of the seizures. Here, she relies on those seizures that she has witnessed as opposed to those that she has experienced, and she shifts into the unpleasant experiences that she associates with witnessing these events.

4.3.3 Witnessing others: “I’ll just keep it separate from me.” This early introduction regarding Hannah’s perception of others’ grand mal seizures places her at a distance from epilepsy and the more visible seizures. In her written narrative, Hannah described a teenage classmate who experienced a visible seizure and she reflected on her decision to separate herself from him. When I asked her about this memory, she appeared to demonstrate her distancing by recounting her role as a “witness,” and as a passive observer who chose to leave the situation in order to keep a separation between the other and his seizure experience:

I don’t think I ever talked to him, or I don’t remember ever going and talking to him, it was just kind of like, “Well, I’ll just keep it separate from me”... right? You know, I didn’t want to have that bonding experience around it with him. I think probably I just, I didn’t want to identify maybe with that...you know, with him on that level or to see myself going up there. And I think I probably, it was a bit of, you know, I didn’t like seeing that in myself, like seeing him I don’t want to see that in myself too. Because like, it’s hard to see, you know when you’re having your own seizure you can’t see necessarily what you look like but when you see someone else, it uh... it’s just, it doesn’t look good or nice or you know... (Pause.) It’s revolting on some levels, right? Because you’re frothing at the mouth and you’re biting your tongue and you’re... your arms, or your mouth and your eyes are all twisted up and you know, it’s hard to see that.

Hannah began the passage by describing her classmate's seizure, but then quickly shifted to her discomfort witnessing the experience, particularly due to a desire to keep a separation from the identity of someone who experiences seizures herself. She appears to associate with the role of the "witnessed," when she shifts to the description of "myself" and descriptions of what "you" are doing during a seizure, which explores her discomfort being witnessed during what she has experienced and perceived to be an unpleasant experience for herself and others. She quickly shifts the focus back away from herself to the seizures that her sister recently experienced during an infection with encephalitis. This reflection suggests that Hannah may have used her sister's more recent seizures to gain comfort with the experience— both as a witness and as someone who has been witnessed having grand mal seizures:

Like I'm thinking about my sister now because she was... you know, like totally, you know, kept having twisting and seeing things when she was in the hospital and it was hard. Especially with her because she's my sister, but it was good, on the other hand it was good to be there. It was like... it's okay... you know, I love her and it's not like, you know, the worst thing you could be seeing, right?

Hannah emphasizes, "we're going to get, she's going to get through this," simultaneously voicing the thoughts of an individual who has been through this experience (i.e., "witnessed"), as well as the role of the supporter (i.e., "witness").

4.3.4 The witness framework. Overall, Hannah uses the witness-witnessed framework to maintain control of the seizure narrative, enabling her to provide a coherent narrative and empowering her to own the narrative. She is able to describe her perceptions as the "witnessed" preceding a seizure, then shifts to her observations as "witness" of one's appearance during a seizure, and finally shifts back to the "witnessed" in describing recovery stages and reconstruction of one's experience after the seizure has taken place. In this final stage, she is able

to provide an ostensibly shared “witness-witnessed” construction of her experience, by describing her role in supporting her sister through the recovery process. This evolution of her role is explored when she is asked to reflect on whether her view has changed these years later, when I asked Hannah whether or not she would now choose to have others present if a seizure were to occur:

Hannah: *I like the idea of people being around to support me in terms of, you know, uh... like waking up and having that support, like if you have a grand mal people would be there and people would be seeing how you're doing and all that kind of support afterwards, it's nice. Cause it's... it's just reassuring because if you have a headache or you need water or you need help to get to lie down or all those kinds of things, right? It's like that caring concern is very... appreciated, or would be appreciated, right?*

Me: *Mm-hmm.*

Hannah: *Umm, actually witnessing the seizure, I mean... I don't know if I necessarily would want, like it's kind of like: "You don't have to necessarily see me have a seizure but after I have it, then you can come and help me," you know?*

This passage again reflects Hannah's reluctant shift between two spaces: an individual who is accepting of her seizures and expects the acceptance of others, but also a reluctance to be witnessed. In essence, Hannah describes a desire for all parties to be absent for her grand mal seizures, in the same way that she is consciously absent.

Hannah's recounting of the seizure narrative from a social perspective, as a “witness,” provides us with a glimpse into the larger narrative framework of her epilepsy identity. She demonstrates her focus, a need to find balance and control over her epilepsy, in two additional ways. First, she further recounts her seizure narrative from a physical perspective, with her

seizures housed by her body, separate from the spiritual mind that houses her identity. Next, she frames her identity as a whole not as a witnessed victim or flawed physical being, but as a witness to others and a mindful caregiver who has learned about epilepsy. Hannah's seizure narratives provide a helpful glimpse into these identities, as we watch her shift between roles when it is required by her illness and by her self.

4.4 Hannah's Physical Seizure Narrative: Mind-Body Separation

The first seizure narrative upon which I focused was Hannah's social positioning as a person who is both witnessed and a witness to seizures. Another prevalent concept in Hannah's narrative is her characterization of her body as the blemished entity that houses the experience of her seizures, while her mind attempts to manage these experiences. I identify this as her physical seizure narrative to emphasize Hannah's focus on her body as the blemished entity, though I will still be addressing the social implications of this portrayal. Hannah described confusion related to the first time she experienced an inability to control her body; notably, she has reframed it in such a way that her mind can form a healthy relationship with her body so as to control the occurrence of a seizure. Consistent with her endorsed training and belief in alternative medicine practices, she presents energy as the method of communication between the mind and body. By reframing her seizures as something to be controlled through energy management, Hannah conceptualizes a relationship between her mind and a subordinate body that lays victim to seizures. My perception was of a woman who was accepting of the fact she may not have control of her body, because she was able to learn to control the energy that it houses. This mind-body hierarchy is consistent with individuals who associate spirituality with their seizures (e.g., Curry, 2006; Kissing, 2003; Seaborg, 2015), in which they rely on spiritual aspects of the self to increase feelings of psychological or physiological control. This mind-body conceptualization and has also been

identified in individuals restoring “perceived control” after the occurrence of the first seizures (Velissaris et al., 2007; Wilson et al., 2004), as well as in those utilizing “alternative medicines” such as reiki and yoga to treat epilepsy (Ricotti & Delanty, 2006).

4.4.1 The “malfunctioning” body. Perhaps in an attempt to distance her mind and potentially her concept of “self” from the seizures experienced by her body, Hannah uses metaphors that present her seizures as mechanical malfunction. This appears to distance her identity from the shame associated with the seizure experiences in her earlier years, instead framing the experience of a seizure as purely physical:

I don't think I'm so ashamed as I may have been years ago, more ashamed that I don't want people to see me but now, if I had that it's like, what's the shame? I mean it's just me, my body doing something that is... malfunctioning, right?

Hannah describes seizures as her body “malfunctioning,” “a significant body event,” and described how she “just moved in autopilot,” all suggesting a mechanical or hollow vessel in which her self is not present and for which she should not be held responsible. Plug and colleagues (2011) have identified epilepsy patient metaphor use regarding the seizure as “a mechanical process” and “disconnection between mind and body,” highlighting that these metaphors are common in both biomedical and lay discourse regarding brain function. Attributing seizures to the dysfunction of the body is not only consistent with the lay discourse, it may also minimize the perceived shame or moral responsibility that individuals, including Hannah, have regarding seizure occurrence (Jacoby et al., 2004; Schneider, 1988). Hannah suggests that seizures are her body’s mechanical dysfunction, a rationale for why her mind/self should not hold shame for the dysfunction of a separate mechanical and physical self.

4.4.2 Getting in touch with the body. Hannah emphasizes that it is her body and not her mind that experiences seizures; however, she suggests this mind-body separation as a unique experience that occurs only during a seizure by describing her mind and body as “disconnected” during seizures. Hannah identifies herself as “out of sync” during a seizure, perhaps suggesting that she may be providing an inconsistent portrayal of a seizure, in which the two entities are involved and are not “in sync”:

Well, I wonder, I think, sometimes I think, “I think this happened this way” ... because I’m trying to piece it together because often times with a seizure too, I think, “Well, I think this happened this way and that happened that way” ... you know, with certain seizures but really, you’re out of sync at the time, you’re not always conscious and you’re coming to and you’re ... so did it really happen that way or am I, is it all, you know, how clear is it?

Both Hannah’s seizure descriptions and her identification of feeling “out of sync” seem consistent with individuals who emphasize the experience of reduced consciousness and reduced self-control as central to the seizure (Schwabe et al., 2008; Surmann, 2005). Individuals who describe this “gap” as a disconnection between the mind and body during seizure tend to use metaphors in reference to a struggle. Hannah’s struggle with a loss of bodily control appeared to lead her to question where her spirit is during a seizure. What appeared to build on her perception of her mind as separate from her body during a seizure was her reflection on spirit during a seizure. When she addresses this spiritual self she portrays a subordinate role for her body, which she believes can be controlled:

Hannah: “Where is my spirit? When I’m not fully conscious and present is it ... is it, still there or is it connecting somewhere else? Does that make sense? Like exploring.../

Me: /Ya./

Hannah: */that kind of dialogue, like does... you know, some people have talked about having epilepsy or that kind of condition brings about more, like, shamanistic kind of qualities or... that kind of tendency to access the more intuitive or more sensory kind of experience and I think, I've explored that for sure in my work and I've gone down that path and I, I feel that I've definitely, I have... that ability to access and be more sensitive to energy and awareness of that. You know? Because I've had to develop it within my, or I feel like I've... it's been a choice I've made to get in touch with my own body so that I can help to be aware of it and control it so to speak, you know?*

Hannah seems to emphasize that it is the awareness and management of energy in her body that allows her to control her seizures. The above quote indicates her belief that not all individuals are aware of this mind-body separation, and that sensitivity towards one's physical energy has a tendency to be more prevalent in those with epilepsy. While there has been acknowledgement of the use of complementary methods to manage epilepsy, Hannah's reference to "shamanistic" qualities reflects a trend towards historical beliefs rather than current practices (Ricotti & Delanty, 2006). She makes reference to becoming more "tuned in" to her body and her energy. Here, she shifts back to her struggle to reconcile these separate entities by increasing her mind-body awareness; rather than conceptualizing her Self as entirely separate from her body and attributing all illness-related events to it, she attempts to accept ownership. She emphasizes that this is a choice she has made to attempt to work and connect with this damaged vessel, rather than abandon her body.

4.4.3 Mind and body: Holding energy. Hannah's perception of energy control is perhaps best illustrated in her description of a seizure that she experiences after the birth of her first child. Hannah described working hard to establish a sense of energy control and seizure

management in the time that she was off medication, from age 27 to 38. Her experience with her first pregnancy appeared to re-introduce a struggle she may have thought she had mastered. A seizure that she experienced after the birth of her first child had Hannah returning to the question of whether she should trust her mind and body, ultimately fearful of losing control:

So most of the time I'm in, in the trust mode but the fear comes sometimes, you know and it's not all the time, but so, when he was born especially it was heightened and that was the last time I had a seizure because I was lying in bed and I, I ugh, I remember thinking, "I'm going to have a seizure right now." I could feel it coming on and I knew I could stop it, cause I can stop them, but I just thought, "Oh I don't... I'll just let it happen." Cause I just wanted to release the energy, cause I felt I had been like, for a month and a half just on edge, like, "Oh my god, I've been taking my energy and holding control and I can't," you know? It was just like, "I'll just let it go." So I was lying in bed and I could just feel my body releasing, letting the um, energy go and it wasn't like a full blown grand mal but I bit my tongue a bit.

Hannah describes her control over her seizures in the instance after she has given birth to her son, and the way in which she chooses to release her energy and permit her body to have a seizure. This description portrays Hannah's increased energy control over her seizures, and further details her desire for a united Self in which mind and body can co-exist without needing to be on guard. She again reflects on the difficulty she has in not being able to come to full reconciliation with her body based on the seizures that it houses. Hannah explained that she knows what it feels like to "be in the fear" but she is constantly trying to find safety and grapple to find what it feels like to "be in the trust," explaining that she trusts her mind but the "it" that

she refers to — the uncertain possibility of a seizure with which she is trying to build trust — is in her body:

Ya, I think for me how I define it as more in my body. That's how I talk about... it... is always in reference in, "I need to trust my body." I have to just be in the trust, not in the fear.

Her description illustrates on one hand, a seeming confidence in her ability to control her energy, but also a caution that she does not feel she can always trust this to be the case. This may reflect her idealized level of trust in her body, as opposed to that which she feels when she perceives a loss of control during a seizure (Velissaris et al., 2007).

4.4.4 Mind and body: Releasing energy. Hannah's challenge in trusting her body is also reflected in other aspects of her life. She introduced ongoing struggles in trusting her body in the context of sexual intimacy. Hannah explained that her husband had never witnessed one of her grand mal seizures, but rather the primary way in which epilepsy impacts her relationship with her husband has been her difficulty trusting her body and feeling comfortable in times of sexual intimacy. Of particular interest here, Hannah seemed to identify her husband as an external witness to the experience she is having with her body. Below, she described her husband as a supporter as she attempts to build safety and trust with her body, which is tentatively portrayed as both connected and separate to her Self:

The intimacy of getting close with [my husband] again, it relates to the letting go of control and that kind of thing and my body maybe, like, being able to let go and have an orgasm or let go of control is... is something that I've worked with him a bit around and trying to just, "It's okay, I can be in my body, I can feel," you know, like, the kind of feeling of... building safety and trust and testing my body, that it's okay and I can let go

and release and it's not going to take me, if I have a release or something, that, having those involuntary motions does not mean having an involuntary seizure, which... ya, it's just a process you know, to kind of, to... ya, reassure myself of that.

This is yet one more account of Hannah's energy awareness, and of her faith in her spiritual mind to control what she seems to characterize as a subordinate and separate physical self. The language she uses to convey these entities varies but generally appears to imply a separation between spiritual and physical energy. Hannah's ongoing struggle is reflected in her statement that she is attempting to come "to terms with embodying my spirit within" perhaps indicating a desire to trust and integrate her mind and body, but a tentativeness to do so. Ultimately, she describes a deep relationship with her body in which she must listen to it, but a reluctance to trust a body that might betray her by having a seizure.

4.5 Beyond the Witness: Epilepsy Identities

Another reflection of Hannah's attempt to manage her illness involves the control of her identity as an individual with epilepsy, and the impact this identity has on the roles she plays throughout her life. The shifts observed in Hannah's witness-to-witnessed control of her seizure narrative, as well as her mind-body conceptualization of seizure control, can be considered as significantly impacting the roles that she plays from diagnosis to present day. A prevalent theme in epilepsy narratives involves information management in terms of individuals determining how and to whom they disclose their epilepsy (Kiliñç & Campbell, 2009; Nijhof, 1998), which has been suggested to portray a shift in identity from that of a "healthy individual" to an "unhealthy individual." Hannah takes an even stronger stance, shifting from identity of "victim" to her epilepsy, to that of a "healer." In many ways, this could be observed as an extension from her early seizure experiences in the role of "witnessed" that transitioned to a "witness" and supporter

to others. While these roles do present in a linear trajectory, Hannah nonetheless demonstrates some shifting between roles as impacted by her illness. Each social role that she plays, from childhood (daughter and sibling), to adolescence (peer relationships), to adulthood (parent and health professional) appears to be affected by her illness in different ways.

4.5.1 A victim. In both her written and oral narratives, Hannah frames her epilepsy diagnosis first as seen through her parents' eyes: *"My parents were obviously upset and not sure what to expect. I assume that they just hoped that I would be relatively normal and function at the same level as before."* (Written narrative) In her oral narrative, Hannah elaborated on her mother's reaction to her first witnessed seizure and diagnosis. She explained that her mother treated her as a "victim," which Hannah chose to rebel against:

I think I could have been smothered by that victim energy, you know... "Oh-h-h, you could just stay home and oh-h-h..." I mean, she just would have let me be the victim and not necessarily be active or do things. I was like, "Well, no, I'm just going to, I'm not doing that, I'm just going to push through and be... what I want to. Not let her limit me.

Of particular interest to me is Hannah's reflection on her mother as being the limiting force, as opposed to her epilepsy. She describes that she is "going to push through" and "not let her limit me," characterizing her mother's reaction to the diagnosis and her perceived victimization as the source of any limitations. While we hear metaphors of battle and resistance from Hannah, the majority seem directed at her mother rather than at her illness. This may be a defensive move, as she identifies it as her own choice not to be a victim. Beyond her professed choice to live her life without being limited, she also describes attempts to protect and comfort her mother. This shift in identity appears to parallel the move she portrays in her seizure narrative, from a "witnessed" or injured "victim" to one who is a "witness" not to another's

seizure, but to her mother's emotional concern. She describes supporting her mother when Hannah's own epilepsy was emerging, as well as more recently when Hannah's sister experienced seizures due to encephalitis. Hannah seemed to portray a role reversal as a child caring for her mother after the child's seizures were witnessed. She elaborates on this caregiver role for herself when supporting her sister and mother in the management of her sister's seizures. She described how seeing her sister have a seizure was upsetting but she nonetheless remained composed and supported her mother and sister through the experience. The protective role that Hannah describes playing since her diagnosis with epilepsy portrays her not only as someone who is not a victim to her illness, but beyond that she portrays herself as a caregiver and healer.

4.5.2 A peer. Hannah portrays a sociocultural awareness of seizures and epilepsy that may have influenced her identity development in relationships with teenage peers. In her written narrative, Hannah addressed the need to "fit in" as a challenge that she faced in identity development in her teenage years, when her epilepsy was first diagnosed:

I just went back to school, as usual, and told my friends what I was diagnosed with. I remember that for me, right away, I did not want to be seen as too different. I wanted to continue fitting in with my friends. (ask the girls...) They were all very accepting of me and I do not remember anyone making me feel like a leper (as was the historical belief that epileptics should go on the leper island as it may be contagious). (Written narrative)

She describes a fear that her friends might reject her or not want to be associated with her, reflecting the perceived stigma, not enacted stigma, that many have identified as having a greater impact on the identity development of many individuals with epilepsy (Jacoby et al., 2005; Kirchglässer, 1990). Hannah further reinforces the externalization of epilepsy and a struggle for control of her identity when she articulates that she did not want to let "this" (seemingly in reference to her epilepsy) impact her relationships. Based on her narratives, Hannah's search for

a sense of identity that incorporated her illness seemed to transition from a fear of being victimized by peers, to one of overcoming illness largely by relating and supporting others with disabilities, consistent with a trend of one's level of acceptance of her or his epilepsy as predictive of the progression of illness identity development (Kirchglässer, 1990, Kilinc & Campbell, 2009). Hannah reflects on her years as a young adult and explains that her experience of seizures and of a chronic illness more generally played a role in the development of her identity and her career. While Hannah acknowledges her involvement as an attempt to "help other people either like myself or similar to myself," she shifts to distinguishing others as more needy than herself and emphasizes not wanting to be victimized or to experience empathy as there are others who are worse off than her. While her written narrative focuses on her early experiences with peers, her oral narrative focuses on more recent years and the impressions that current peers have of her and her illness. She openly states the ability that she has to overcome many illness-related hurdles and live with epilepsy as a primarily "invisible condition."

Hannah: People are just like... you have epilepsy? They just can't believe it, I guess they're shocked because I don't, I mean, I never, I guess I've never said, "Well, what do you think?" But I guess they just, like, "Wow, I can't believe you do, how do you cope with it or what do you do or..." you know?

Me: So how do you feel when you get that reaction?

Hannah: I... I guess I feel good because... they don't see, they don't see this invisible, uh, condition that I'm living with, right? Not that I want everybody to see it either but it's just like, when they do recognize it and say, "Well, you're coping with that and you're doing well." And that's good.

Hannah's thoughts appear to reflect a reluctance to make others aware of her condition at the risk of being "victimized"; however, she expresses pride at the positive affirmation and

validation she receives when others acknowledge her ability to cope with the challenges that epilepsy has posed in her life. Hannah describes many shifts from her early 20s into her adult years, she describes the theme of trying to balance or “do the dance” between being productive and successful according to her own standards, while maintaining awareness of her physical needs and ultimately the way in which her actions impact the possibility of a seizure.

4.5.3 A mother. In her adult years, Hannah portrays her role as a mother as one in which she appears to experience a heightened responsibility and need to apply what she has learned from her epilepsy (e.g., physical changes, energy control, etc.). This role is one that she discussed in great detail in both of her narratives, indicating that it likely dictates how her relationship with her illness is perceived and continues to evolve. When asked about how she discussed her epilepsy with her family and children, Hannah articulated ways in which she had attempted to overcome the “victim” identity she knew in her childhood:

Well, I know one thing that I feel that I've always tried to, and I'm not sure when I started, but to really not identify myself as, uh, an epileptic, you know? But... I have epilepsy, so I've always been really, felt really aware of that. That I am not that... I'm more than I am and I have epilepsy. Just that kind of differentiation of, that I'm not, I'm just not that identity itself you know?

Here Hannah seems to reiterate a need to prove that she can overcome her illness and her physical limitations by insisting that she can recover and return to a productive individual, and given in the context of her role as wife and mother, there may be an increased desire to demonstrate that her illness had minimal impact on these roles. Hannah emphasized that her husband had never had to witness or care for her during a seizure, explaining that her epilepsy would not be a concern for their relationship if it were defined by seizure activity alone. She

nonetheless identified a challenge as related to sexual intimacy, as she continued to struggle to let go of control of her body.

In describing her role as a mother and caregiver, Hannah demonstrates conflict in feeling that she cares well for her children but is nonetheless reliant on others to help her manage the impact that her illness had on her children. In particular, Hannah focused on the challenges that she experienced following the birth of her son, making the noteworthy choice to go back on medication. While this medication was a treatment for her own medical condition, she described this action as her duty as a mother. Despite descriptions of trying to limit and eventually be “medication-free,” Hannah made it clear that this would not be something that she would attempt until her children were older and less in need of her undivided attention. She referred to her medication as a “safety net” that allows her to be less vigilant in case she is unable to attend to her physical needs through mindfulness and her own health approaches.

4.5.4 A healer: Western and Eastern medicine. Every participant that I interviewed, as well as many narrators of the published and unpublished narratives that I read, described power struggles with their physicians or with the medical system related to the medications that they were prescribed to manage their seizures. In the following quote, Conrad (1985) presents an early and frequent finding regarding individuals with epilepsy, in which many have been found to seek control over their epilepsy by managing their own medications:

Regulating medication represents an attempt to assert some degree of control over a condition that appears at times to be completely beyond control. Loss of control is a significant concern for people with epilepsy. While medical treatment can increase both the sense and the fact of control over epilepsy, and information control can limit stigmatization, the regulation of medications is one way people with epilepsy struggle to

gain some personal control over their condition.

The physicians in Hannah's narrative play a relatively peripheral role and are identified primarily as an embodiment of her relationship with medications. She generally distances herself from her physicians and describes their role in her diagnosis or their perceived stance on medication. The largest role that medication plays in Hannah's written narrative is her desire to be "medication-free;" she described negative experiences with medication and a desire to heal herself and to do so without Western medicine. When I asked her to describe the "medication-free" identity, she focused primarily on the impact of medications on her mind-body connection:

Me: What was that [medicated] identity like? What's a medication-free identity and how did it contrast?

Hannah: Well it's interesting because it's hard to... I don't know if it's more the concept of it or the actual experience of it, right? Well, for sure the difference when I was on phenobarb and that, I didn't like that. Because they made me feel more drugged out and like, just more, not in my body I guess. Just feeling a bit more cloudy and my reaction time to things was not good. I mean, it was not like huge but I was aware, I was just, it slowed me down a little bit.

Hannah describes conflict and struggle with physicians, family, and her own body regarding the decision to be medication-free. She described different social opinions of her choice not to use medication for a period of time, explaining that her parents were not fully supportive, she did not have a "doctor's blessing," but that her friends and sister were supportive. Ultimately, Hannah identified herself as courageous for choosing to "*challenge myself to just experience my body on its own accord.*" Hannah described having faith in herself and the many modalities which she has used to gain control and understanding of her body (e.g., meditation, yoga, massage, cranial sacral therapy, reiki, energy balancing). Hannah identifies that "*epilepsy*

has taken me down this path of healing,” attributing her healing journey and ultimately her fields of employment as heavily influenced by her illness.

She describes a power struggle, both with physicians and perhaps more so with herself, as she attempts to reconcile why she has chosen to go off medication. Hannah emphasizes a need for solid relationships with physicians and a belief that she will receive negative feedback if she discussed her choice to discontinue medication. Dramatic though it may be, her indication that she was *“taking my life in my own hands and my control over my own body”* emphasizes her choice towards independence from the medical system and the ongoing theme of her perceived ability to control her illness and its treatment (Velissaris et al., 2007). While she acknowledged experiencing seizures over the time that she was medication-free, she rationalized that these were relatively well controlled through homeopathic management, and closed with a “quest” to again retain full control without medication:

I think eventually I'd like to go off medication again or try to reduce it. I'm always thinking that. “Oh ya, I could reduce that.” Eventually... like this quest for... I don't know... and I don't necessarily know why because, or that why is that so important to me that I want to be off medication, you know?

Conrad (1985, 1992) identified a subset of individuals who report “practical practice” of taking medications during times when seizure occurrence might be more likely or have greater implications. This appears to be reflected in Hannah’s indication that her role as a mother requires her to take medication until she can later reduce her medication.

Hannah’s written narrative involves much discussion of her preference for Eastern medicine traditions over Western medicine, specifically as they involve limiting her medications. It is noteworthy that she framed the treatment approaches not only in terms of different modalities, but that she also demonstrated a preference for treatments over which she has control,

both by gaining understanding and mastery of treatment approaches. She describes with pride her ability to manage her seizures through the use of these methods and attributes this path of training as inspired by her epilepsy and her search to heal others like her. This reflects a theme of “self-regulation” as perceived by individuals with epilepsy, while medically-centered approaches characterize this as non-compliance with one’s medical regimen (Conrad, 1985, 1992). While “non-compliance” has been biomedically defined as the individual not taking medications as prescribed and instead managing their own medications, individuals such as Hannah may perceive their treatment within a greater psychosocial framework incorporating the management their epilepsy through medications, seizure awareness, and alternative therapies (Conrad, 1985, 1992; Ricotti & Delanty, 2006). She also takes this a step further by taking on the role of healer of her own body and those of others. She describes with pride an identity that she identifies as having been inspired at least in part by her epilepsy, as a professional masseuse and energy healer.

4.6 Transitional States

Hannah’s framework and the labels she uses to portray her transient experience of symptoms (i.e., shifting from physically stable to seizure occurrence) appear to extend to a transient experience of epilepsy identities with constant shifts from someone who is “healthy” to someone who is “ill.” Hannah describes her “healing journey” as a conflicted one, as she seeks to accept her epilepsy, but at other times she seeks to rid herself of epilepsy by healing and honouring her body:

Hannah: You know, I’m feeling, I think more content with my body and my relationship with my epilepsy. I feel content. But I always, at the same time I always have this piece of wanting it to be resolved too. So there’s... there’s a discord that’s there. That is not like, “This is it. I accept you 100% and... you know, you’re, the epilepsy in my life,” like I... I

accept it in my life but at the same time I'm always trying to umm... have it cleared totally from my life. So it's like, which you know it's kind of like... I know that uh... modern medicine or... might not ever see that as a possibility...

Me: /Mm hmm/

Hannah: */but I still hold out that hope for myself that, eventually, on a... for me I see it more like on an energetic level that I can heal myself and clear the need or the energy around that and be totally seizure free... But at the same time, it's that paradox, because I also accept that this is, you know, not, it's not like I'm fighting it all the time or, you know? I accept that this is where I am at with it.*

The progression of Hannah's "healing journey" appears to be an attempt to reconcile elements of herself that she perceives as truly separate. The most distinct separate entities are her physical self, as impacted by epilepsy, and her core identity, which she identifies as her mind or spiritual self. Metaphors of struggle, such as "fighting it," are common in descriptions of mind-body conflict in seizures (Schwabe et al., 2008) and in epilepsy (Surmann, 2005). Hannah presents a complex struggle in that she identifies acceptance of her illness and is not "fighting it all the time"; however, she strives to be seizure-free. She identifies herself as reconciled and willing to give control to her body, her physical illness, and her medical label; nonetheless, she identifies her spirituality as her way to gain control over an illness that she cannot physically control. Hannah acknowledges this tension between these multiple entities in many ways: as existing on different "levels," attributing percentages towards different attitudes, "dancing" between layers of existence, and perhaps best in her description of transitioning from light to darkness during a seizure: "it's that place of in-betweenness."

For me, Hannah's references to living in transience or "in-betweenness" introduced the notion of liminality. Traditionally, liminality was introduced as a social transition from one state

to another (e.g., from childhood to adulthood) through a ritualized rite of passage in which the individual existed as a liminal being in the passage from one state to another, having given up traits related to his or her past state and having not yet claimed the new traits related to the future state (Turner, 1987). States Turner (1969): “Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (p. 95). A small number of health researchers have considered liminality and have characterized it in different ways depending on the illness; it has generally been used to indicate individuals involved in a transition from a “healthy” identity to a new, yet-to-be defined “unhealthy” identity (Jackson, 2005; Little, Jordens, Paul, Montgomery & Philipson, 1998). As we will examine in the following passages, Hannah frequently reflects upon and appears to exist in this transitional space.

4.6.1 Liminality and seizures: Light and darkness. Hannah references light and darkness associated with the shift she experiences during her seizures, and extends this reference to her experience with epilepsy. When asked to elaborate on her written reference to light and darkness, she provided me with insight into her fears surrounding the implications of a loss of control:

I just have visions or I can remember different times when I've had seizures where it's just that instance of falling, falling, it's that falling sickness... it's like you're all of a sudden you're free falling and the light is going out and you know it's coming and you know you're gone and so... it's, you're in between, it's that place of in between-ness, between the light- which I want to stay in the light- you know I want to, that's vital life-force energy, it's like engaging and empowering energy and where going into the darkness is, it feels, well it feels... draining and it's, you know, it's dark, it's death, it's a

negative kind of energy, you know, it's not supporting me, it's not nourishing me... it's like negating my body, my experience, my self identity, it's kind of like a negation of that in a way.

Hannah's characterization of light and darkness provides a rich metaphor of the shift in energy between from light— a state of stable and desirable sense of being — to darkness — a state of uncertain and negative sense of being. Hannah characterizes light as positive energy, “engaging and empowering,” and “being in my power,” emphasizing the control that she associates with this energy state. She characterizes darkness as negative energy associated with seizures, panic attacks, and a loss of her ability to control her body. Hannah's description of “in-betweenness” provides a helpful portrayal of the brief moment in which she is aware of a loss of control over her energy state. The concept of a state of “in-betweenness” for me was an interesting illustration of liminality, embodied here as a transition neurologically and psychologically. In an instant, Hannah shifts from someone who is managing her own cognitive and physical responses to someone who does not have control over these elements of self, consistent with a liminal transition (Jackson, 2005; Little et al., 1998). A further illustration of this liminal experience was Hannah's description of existing on the “edge” of the in-between space where she shifts from a myoclonic jerk to a grand mal seizure:

Me: So, the jerks? You still feel it's a light and dark kind of experience?

Hannah: Ya, with the jerks when I'm feeling them I know it can... I'm not seeing lightness or... I'm in the light, so I'm not going right into the dark but that could be coming... that feeling of, just you know, it just catches me and holds me. You know, that kind of thing... So ya... it's kind of interesting cause it's that kind of wanting to be in the light, to stay in the light and... the energy.

In contrast to her description of feeling in control of her seizures, Hannah describes the ominous possibility of an externalized “it” that “just catches me and holds me.” Plug and colleagues (2011) identified this as a common type of epileptic seizure description, with many epilepsy patients reporting their seizures as “actions performed by an external agent” (p. 219).

4.6.2 Liminality and epilepsy: “a potential storm.” When directly asked what metaphor she does use or would use to describe epilepsy, Hannah described a storm, which appears to reflect her experience with seizures and epilepsy in numerous ways. Hannah’s description of a storm incorporates the light-dark dichotomy that she identified, as well as the transient nature of shifting between two levels while time moves forward:

Epilepsy... it’s like, um... it’s like living with a... I kind of get this image, it’s like living with a potential storm about to, um, appear, like lightning flashing and... it’s like that storm cloud is there but not always there. It’s like lots of times sunny and bright and it’s not there at all... and the grass is growing and there’s birds and it’s sunny but then all of a sudden a storm can come, the cloud is there, it’s grey and all of a sudden lightning can strike and... and then it can go back to being sunny again.

Hannah’s unpredictable “storm” metaphor is of interest because it does not imply that Hannah has control over the physical elements in the way that she suggested throughout much of her narrative. Instead, it is consistent with her description of light and darkness, in which she emphasizes the uncontrollability of the seizures and the darkness with which she equates them. Perhaps what we are witnessing is a greater acceptance of the inevitability of these shifts in energy, including greater acceptance of what Hannah can and cannot control.

4.6.3 The liminal element: An “engrained” epilepsy identity. Hannah portrayed herself on a constant journey forward in that she attempts to push onwards while attempting to

shift between identity roles of witness to witnessed and victim to healer, and also between her mind and body by managing her energy. Her attempt to manage her energy may also be interpreted as an attempt to maintain control of her narrative, with the frequent discussion of energy imbalance when she is faced with unpredictable challenges. She identified her epilepsy as “cyclical” in nature, due to epilepsy reminders and experiences that continue to resurface both predictably (e.g., medications, doctor’s appointments) and unpredictably (e.g., seizures):

Sometimes I don’t think of it at all, that it’s a part of my life at all, and then at other times it’s just really in my face in terms of how I deal with epilepsy daily and how it affects what I do or don’t do, or all those kind of things. Because I think it’s that kind of thing that when you live with something, a chronic illness it just, a chronic condition, it just becomes so... ingrained.

Hannah’s description of her illness as “ingrained” is a helpful way to describe the constant yet not necessarily consistent existence of daily routines; “ingrained” also helps describe a perpetually liminal status of the individual with a chronic illness (Jackson, 2005). This description may also fit Little and colleagues’ (1998) proposed state of “suspended liminality” in which individuals continuously construct and re-construct meaning, possibly over the remainder of their life course as their illness and identity may continue to change. By learning and obediently making her illness maintenance behaviours part of her routine, her awareness of illness may indeed become ingrained and play a manageable if changing role in her identities (Charmaz, 1991; Conrad, 1985). Ongoing illness-related concerns or resistance to her diagnosis may lead her to struggle and experience a more conscious, prominent role of the illness in her identity. For Hannah, the presentation of illness-related behaviours as an accepted “normal” is what has been considered an “illness-as-normality” narrative (Frank, 2010), with an acceptance

of her daily realities of her illness. What may be present but unspoken in the population that identifies with the “illness-as-normality” narrative population, is that which has been identified in the “remission society” (Frank, 1997) as the acceptance of one’s illness while still idealizing removal of the illness entirely. In Hannah’s case, she describes an acceptance of her epilepsy despite a constant hope for “complete clearance” of her seizures, which she hopes to achieve through her practice of Eastern medicine-based energy control.

4.7 Conclusion: Living “in-between”

Stirling (2010) offers an interesting observation that fictional characters with epilepsy are often located “in the borderlands between normality and abnormality; as a figurative device, ‘the epileptic’ is inevitably poised on an unstable threshold between order and ever-threatening chaos” (p. xv). While Stirling’s reflection is made in the context of cultural representations, this liminal existence parallels Hannah’s numerous descriptions of a life on the “edge” between control of the body and of the epilepsy experience, whether as a physiological experience during a seizure (i.e., mind-body separation), social identity in the instance of a seizure (i.e., witness-witnessed), or social identity as an individual with epilepsy (i.e., victim-healer). An interesting element to reflect on regarding Hannah’s described ability to control her seizures is the way in which physicians might interpret her descriptions of control. As discussed in the *Literature Review*, researchers have distinguished unique patterns in the language used by those experiencing epileptic seizures as compared to those with psychogenic non-epileptic seizures (PNES; Plug et al., 2011; Reuber et al., 2010; Schwabe et al., 2009). This comparison led to the conclusion that individuals with epilepsy tend to portray the seizure as acting upon them (e.g., passes through them, taken in, etc.) as opposed to those with PNES who identify themselves as the active force in the seizure (e.g., enter into seizure, choose to leave, etc.). Hannah locates

herself between these two descriptions, as someone who possesses control and determines whether she will enter the “seizure space” and yet she acknowledges some instances in which her body overtakes her and controls whether her seizure will progress and become more physical. While much of her early life narrative characterizes her seizures as acting upon her, she appears to shift to descriptions of herself acting on her body and controlling her seizures as she gains perceived control as she ages. Based solely on Hannah’s seizure descriptions and perceived control over her body, one may question the extent to which these are epileptic as opposed to PNES, given that she describes herself as the one controlling and deciding whether or not she will experience a seizure.

While Hannah’s positioning as perceiving increased control over her seizures and her epilepsy identity may lead to questions from those in a diagnostic standpoint, this has in fact been a psychotherapy target for individuals with epilepsy. For example, Tang and colleagues (2014) acknowledge the increasing success of diverse psychotherapeutic models, including psychoeducation, mind-body approaches such as mindfulness, and cognitive behavioural therapy that emphasize empowering clients by increasing perceived control over those domains of their life with epilepsy that they are able to control, such as awareness of possible seizure triggers, strategies for coping and making sense after a seizure occurrence. For the purpose of this study, it is helpful to consider the language used and those concepts that appear to facilitate, for Hannah and perhaps for others, a perception of control over her seizures and epilepsy identity, including frameworks such as witness-witnessed, mind-body separation, and victim-healer roles. Because the term “witness” appears most prevalent in biomedical and sociological dialogue surrounding epilepsy, and because it played a role in each narrative collected for this study, this will be the term that we explore further in Chapter 9.

For now let us turn our attention to the narratives provided by Clark who, much like Hannah, appeared to have achieved a significant level of perceived control over his seizures and yet still identified epilepsy as central to his identity. Both Hannah and Clark seemed to identify most closely with the role of witnesses to the seizures and struggles of others, and while Hannah identified herself as evolving into a “healer,” we will observe the way in which Clark identified himself as a different type of supporter.

CHAPTER FIVE

Clark: Mechanics, Saviours, and Captain Epilepsy

5.1 Meet Clark

This interview was one of many interactions that Clark and I had over the course of several years. At the time that Clark's narratives were collected, he was a 57-year old divorced father of three who had moved to Saskatoon five years earlier. Clark was living with his common-law partner and her two sons, one of whom had epilepsy. An illustration of Clark's keen involvement in the epilepsy community was that I first met him at a public lecture that I helped to organize. Over the four years that I knew him, he was acting representative for the local organization for epilepsy. He came across as an upbeat and cheerful leader, always welcoming new members and looking to increase the energy level in the room. Clark was a passionate performer, and it was sometimes difficult for me to jump into the conversation, given his strong presence. He was eager to increase public awareness about epilepsy, and to share his own story in particular.

In both his oral and written narrative, Clark encouraged me to watch his YouTube video in which he spoke at a hospital forum for those with epilepsy. This circumstance was then unique, in that I had three sources of Clark's narrative to consider. I treated Clark's video as the information that I collected prior to the formal oral interview in the same way that I treated any conversations or email interactions that I had with other participants. This afforded me the opportunity to note material, such as metaphors used or unclear elements of his narrative, that I wanted to follow up on in the formal interview setting.

Our interview took place in Clark's office, which was decorated with plaques, awards, and pictures reflecting his involvement in community groups, both those related to epilepsy as

well as other social and health-related organizations. Clark had difficulty staying on topic though he covered the same core narrative linkages shared in his other narratives (e.g., written, video). Given my priority of observing the participants in whichever manner they chose to tell their stories, the interview moved in many directions. I did my best not to redirect Clark but prompted for more detail when I felt it necessary to make sense of his statements or unique uses of language. In many instances much more detail was provided in our conversation than had been in his video or written narrative. As with the other interviews, I occasionally reviewed the list of topics that I wanted to ensure were covered in our interview.

It was interesting to note that Clark's written and oral narratives were even more animated than his video, a speech to an audience of physicians, peers and family members living with epilepsy. My interpretation was that this was likely due to the comfort level that Clark had, knowing that he was writing and speaking to one individual that he knew rather than an auditorium of peers, strangers, and professionals. The fact that this presentation was also attended by physicians may also have influenced the nature of his discussion regarding communication with physicians, as he was much more critical in our interview.

5.2 Epilepsy: Mechanical Versus Spiritual Interpretations

Clark appeared to have a multi-part interpretation of his epilepsy experience. He began with a narrative that conveyed factual information about his epilepsy told in chronological sequence from his first seizure, diagnosis, and treatments, using biomedical and mechanical terms. As our conversation progressed, he made it clear that his experiences with epilepsy were central to his identity as a whole and had impacted him well beyond the biomedical realm, identifying himself as Captain Epilepsy and Mister Epilepsy in both his written and oral narratives. There exists a level of chaos in his narrative, however, and the divisions between

certain aspects of his illness experience seem largely defined by the sources of his language (e.g., biomedical terminology, self-given titles) and form (the way in which this language is used, from animated stories to one-word statements; Radley, 1993; Schwabe et al., 2008).

First, Clark described his epilepsy as a biomedical experience, akin to the disease side of the disease/illness conceptualization (Conrad & Barker, 2010; Kleinman, 1988), which focuses on medical discourse of epilepsy as a physical condition and mechanical language to convey the machine-like functioning of the body. He seemed to prioritize the need to appear knowledgeable on the topic of epilepsy, identifying his mechanical metaphors as a means to educate others regarding “how the brain works.” At other times he seemed to use references to mechanical function without awareness, such as a simple “boom boom boom” or “wham” to indicate the occurrence of seizures. Ultimately, he suggested limitations to the mechanical approach, referencing physicians as “mechanics” who may be limited in what they can “fix,” given that: *“they’re not dealing with a car, they’re dealing with a human being.”* It appeared that, when he became frustrated with the limitations of his “mechanics,” Clark alternatively described many aspects of his epilepsy experience from a “spiritual” perspective.

In the second portion and indeed the majority of Clark’s chapter, we will observe how he used social and spiritual terms to describe aspects of his epilepsy that might be better captured by the illness side of the disease/illness conceptualization (Conrad & Barker, 2010; Kleinman, 1988), which focuses on the psychological and social conditions. He explained that he comes from a spiritual background, and thus many of his descriptions may be a consequence of vocabulary and perspectives that he grew up with, though he explained that his beliefs have changed since his illness began. For example, he labels the medical student who discovered his diagnosis as his “guardian angel,” his current neurologist as his “saviour,” others with epilepsy share “fellowship,” and he identified his informal role as a “preacher” regarding epilepsy. In

fitting with his role as Captain Epilepsy, he emphasized strong but sacrificial acts in which he leaves his family so as not to burden them with his illness. Let us now visit Clark's narrative reconstruction, so as to observe his terminology in action.

5.3 Clark's Seizure Narrative: Solving the Mystery

Clark has told his narrative many times and the opening line seems to be set: "it" began in 1985 but remained an unsolved mystery until 1989. He portrayed frustration that, despite the many descriptions he had given to physicians, his illness remained misdiagnosed until a physical, visible, and medically diagnosable event took place:

Uh, it kicked in in, it started in '85... but it wasn't identified til '89. I was driving on my way to pre-natal classes actually [...] and was driving down the street and, all of a sudden, my ex said to me: "What are you doing?" And I snapped. I was in a, a haze... that's the first time I remember being out of it, and being snapped back into reality, and these... spells... started to increase in frequency. Like I mean it was, it was just one, and I don't remember when the next one happened but it was getting to the point that I was having so many, like it got to the point of so many per hour. So many per day. And, uh, ya it was awful.

Clark demonstrates the power of a medical label in that he himself did not label his seizures until after they were diagnosed, despite the fact that he was telling the story retrospectively (Kirmayer, 2004). Instead, we hear multiple descriptors of his complex partial seizures as mysterious events, including "dreams" and "spells," as well as metaphors referencing transition through a space/place, such as "snapping out of reality," "being in a haze," and "being out of it," consistent with seizure portrayals associated with an external locus of control (Plug et al., 2009a). In later descriptions, he resorted to more medical model terminology such as "loss of

awareness” and “loss of consciousness.” In isolation, these terms present as relatively innocuous; however, Clark’s additional emotional descriptors such as “horrid” and “terrifying” portray the impact that they have had on him. It is perhaps for this reason that his initial diagnosis of “anxiety attacks” did not feel appropriate to him in explaining the symptoms he experienced:

I was treated, as I say in the story, for anxiety attacks and, uh, to me it didn’t make sense that I would, that I would completely lose consciousness, like I mean I was, I would be completely unaware of what was going on around me and then snap out of it. No, not even snap out of it, I would regain awareness, sometimes driving, you know, in a horrific way, sometimes in a, easing back into reality.

Clark described a frustration and resentment towards the psychological diagnosis of “anxiety attacks” that he received. This resentment towards a psychological diagnosis may highlight a perception that his illness was not being validated by physicians, or may reflect a perceived social stigma surrounding psychological illness (Andermann, 2000; Nijhof, 1998). Despite Clark’s self-reported perception of social stigma around epilepsy, his perception of stigma around mental illness appears even greater, with frustration regarding comments that his experience “wasn’t that serious,” was “all in [his] head,” and that he just needed to “calm down” (Baker, 2002; Scambler, 1998). This earlier characterization also placed the moral burden of illness on him, and he emphasizes his own lack of trust in himself when he indicates that he is unable to control these events (Schneider, 1988).

When describing seizures in his written narrative, Clark began with a description of his first witnessed complex partial seizures; however, he quickly shifted to dramatic and detailed descriptions of his visible tonic clonic seizures. When asked about how he became aware of epilepsy, he began by describing those seizures he has witnessed over his lifecourse, starting with the first tonic clonic seizure experienced by a high school friend. Indeed, much like Hannah’s

addressing of seizures, Clark tended to focus on the seizures to which he had been a witness and supporter. All of these seizures that he described were tonic clonic and violent in nature (e.g., smashing into a glass case, broken bones, seizures occurring while holding chemicals). Despite his seeming desire to educate others and demystify misconceptions about epilepsy, his own description is full of the commonly feared, sensationalist seizure descriptions (e.g., violent physical thrashing, flailing limbs) that he himself denounces as those that others inaccurately associate with epilepsy (Baker, 2002). In this way, Clark's seizure narrative illustrates for us the way in which his seizures started off as relatively minor moments in which he would "*stare off into space*" but became dramatic and central to his conceptualization of epilepsy.

5.4 The Mechanical Self: Fixing a Broken Brain

Clark used mechanical motifs in many descriptions of his epilepsy. His narrative suggests that he understands the concept of his body as a mechanical object and the doctor, a mechanic. He demonstrated ease in communicating with mechanical metaphors; it may be that understanding and conveying seizures as mechanical, physical experiences is easiest for him with this language, whether as a result of his own conceptualizations or those that have been provided to him in medical model encounters (Conrad & Barker, 2010). He referenced his first seizure and epilepsy itself as to when "*it kicked in,*" similar to the way someone might describe the first time their car started making a strange noise, or indicating the beginning of a mechanical breakdown. As his experience continued he described seizure activity based on physical damage, explaining: "*Plus the brain, the damage to the brain. Not just the brain damage but the, when your brain fires like that for so long, you have fatigue that you can't imagine.*"

The concept of neurons firing and misfiring has long been used in biomedical terminology, and Clark's is one of many narratives in which this concept has been applied to the brain as a mechanism albeit with this individual's unique interpretation (Räty et al., 2009).

Clark did not endorse the same mind-body division that was expressed by Hannah, but instead focused on the mechanics of his brain as a computer:

I look at it like a computer. There's no question. The rest and all the peripherals, I know is the brain. It's just, I've broken limbs, I've had an appendix out, and problems like that, but I know it's all based in the brain, but I know that. That's something I knew... I don't know if it's something that I've had reinforced so strongly but nothing goes on in my body without the brain involved in it.

He elaborated on this interpretation suggesting that this mechanical brain also controls his mind, including his mood and cognitive function. This suggested to me that he was seeking a treatment to fix not only his epilepsy, but also the mood disturbances that he experienced both prior to and in association with his epilepsy.

Clark addressed his need for treatment much like a mechanical fix; he declares that upon diagnosis of the broken part physicians should have been able to "fix" his seizures. Clark's most detailed use of mechanical language was in his description of his neurosurgery, in terms that he indicated were a collaborative effort between himself and his surgeon. Clark explicitly acknowledges that his language was influenced by terminology that he learned from physicians on the surgical unit, as opposed to that which he utilized beforehand:

Me: One description that you gave of your time in London was finding the ignition and finding the engine.

Clark: Oh ya, no question... The uh... Actually, that's how we discussed it... my surgeon in London described it to me. And together we kinda came up with that analogy, putting

those labels on it. Just the fact that I was having temporal lobe seizures, which are complex partial- you know that. And then every once in a while, if the conditions were right, I had tonic clonic, okay?

Me: *Um-hmm.*

Clark: *So, what happens if things weren't going well, all of a sudden it just goes firing off- boom boom boom- 35 times a day.*

Me: *Um-hmm.*

Clark: *And if things went bad, it would kick off the tumour here (points to the back of his head). So basically what they said was, okay, we have two options. We go in the temporal lobe, try to find the problem.*

Me: *Okay.*

Clark: *Or we, you have this mass, that is a benign, diagnosed as a benign tumour. On your occipital lobe. And so, what we're going to be doing, our plan is to leave the ignition in, but take the engine out... and that was down here (points to the back of his head). So basically, what they thought was that that was the route that my brain had mapped out for me. Because it had been there my whole life, they thought that if they took this engine out then the ignition, it would just be a useless ignition, and that's exactly what happened. So by taking, going in and popping out the engine, and putting it back together, I never had another complex partial seizure, so that's pretty cool.*

Clark's descriptions indicate that he is not only comfortable with the terminology but also that he perceived a sense of empowerment and even ownership over the experience of his surgery, based on his perception that both his treatment and his analogy were developed by himself in collaboration with his physician. His comfort level and concrete understanding of the situation are illustrated in the mechanical terms used, with reference to the function of the

ignition and the engine. Of particular relevance, he labelled the tumour as an engine that got “*popped out*” and his brain “*put back together.*” These terms indicate that this mechanical solution was not only successful as a surgery, but it also provided an indicator of successful doctor-patient communication, thus reinforcing a role for the mechanically-focused terminology used in medical settings (Kirmayer, 2004).

5.4.1 Doctorese: “They’re just mechanics...” Despite Clark’s conceptualization of doctors as the individuals you go to when “*things don’t work right,*” he criticized the physicians with whom he experienced unsuccessful attempts at treatment:

I have issue with any doctor who thinks that because they have an MD they know everything. They don’t. They’re a mechanic. That’s all they are. The only difference is they’re not dealing with a car, they’re dealing with a human being. And the thing is with a car, you know exactly what has to happen. With a human being, you think you know what has to happen.

Clark reported psychological experiences that he associated with his epilepsy such as stress and depression, and these could be considered central to both his seizure and epilepsy experiences, and could further contribute to his seeming difficulty capturing all of his experiences as mechanical, disease-model processes (Brosh, 2011). He expressed the frustration he experienced in attempting to establish an accurate diagnosis when interacting with physicians:

Um, people who know epilepsy in the medical community, even the people who are epileptologists, who are neurologists, even they get confused... about epilepsy. They put a medical twist on it and they miss the reality side of things, umm, so bringing all that back is the fact that... I was extremely frustrated and it took me 3 and a half years to get diagnosed.

Clark expressed his criticism of the medical system's frequent reliance on medical terminology and explained his own attempts to help others understand medical terminology:

I used a crossover language. I used medical and everyday language. 'Kay, if you say neurotransmitters to a bunch of people that you're talking to about epilepsy, who don't know epilepsy, you say neurotransmitters and unless they're medically oriented they have no idea what you're talking about. 'Kay, neurotransmitters, that's where your brain starts to do its work. It connects with the body.

When asked how he made sense of epilepsy in regards to his own diagnosis, he referred to the language that he learned from his neurologist, Dr. Smith. Despite his reported trust and respect for Dr. Smith, Clark still described struggles to communicate. In what he labelled "doctorese," he identified communication difficulties as a challenge for physicians who are unable to make their diagnoses and explanations accessible to patients (Fisher et al., 2005). In part, he referred to a perceived hierarchy in which the doctor is far more intelligent and must be able to "dummy it down" for the patient:

Dr. Smith would explain... the man is incredibly intelligent. He would explain it to me in doctorese. Okay. And I'm, I remember saying to him on a couple of occasions, "Doc, that's great. But what the fuck does it mean?" And he would say, "Well..." And then he would take it and he would dummy it down to a level that I would understand, until I got to the point where he didn't have to do that anymore. And that's a problem, that's a pretty high level of treatment, of diagnosis, etcetera, and I think that the medical community, at that level, has a hard time dummifying it down to patient. Somebody's coming in there because they're having a hard time with their seizures. They don't give a shit about neurotransmitters. They want to know what's going on in their head. They want to know why I'm waking up on the floor and my mouth is bleeding.

Notably, Clark described the empowerment he felt when he no longer had to “dummy it down.” This reflection again highlights his feeling of being back in control of his illness, as well as preparing him to become a leader in educating his peers and the public regarding epilepsy. I found it interesting that Clark did not express interest in the reverse, that is, he did not look for the medical community to understand the patient’s language or priorities.

5.5 The Spiritual Self: Epilepsy As a Religion

In describing his epilepsy as a whole, Clark tended to use terminology that I interpreted as reflecting a spiritual perspective. This applies particularly to those aspects which neither he nor his physicians were able to explain through mechanical terms, and also to those aspects that he perceives to have gone unaddressed by physicians. These aspects seem best captured by the illness side of the disease/illness conceptualization (Conrad & Barker, 2010; Kleinman, 1988), which focuses on the psychological and social conditions implicated in epilepsy. Clark explained that he comes from a spiritual background, and thus many of his descriptions may be a consequence of a strong spiritual vocabulary and perspective, though he explained that his beliefs have changed since his illness began. As noted, he labelled his diagnosing physician as his “guardian angel,” his current neurologist as his “saviour,” himself as a “preacher” to the epilepsy community, and acknowledged the “fellowship” of his peers with epilepsy. He further identified sacrificial acts that he has made for the betterment of others, including leaving his family to minimize their burden and changing occupations to serve the epilepsy community. Many of these characterizations may be opportunities to reframe lost aspects of his identity (e.g., demotion in his original occupation, leaving a marriage), and perhaps to maintain an apparently stronger position as the “Captain” and leader.

5.5.1 The epiphany. Clark described his seizures as initially misunderstood and misdiagnosed experiences, making the correct labelling of his seizures an “epiphany” that marked his new identity. He reportedly did not resist his diagnosis but rather appeared to make his diagnostic label central to his new identity by identifying himself as Mister Epilepsy in some instances, and Captain Epilepsy in other instances. His metaphor use presented this initial diagnosis as well as many later elements of his treatment, as spiritual in nature though not grounded in a particular religion. Clark commented on his initial reaction when a visiting medical student observed his seizure and provided him with a diagnostic label and medical description that matched his experiences:

Oh! I broke down and cried. I mean, it was just... I was so frustrated but all of a sudden, it was like I had been, you know, my guardian angel had hit me on the head and said, “You know it will be okay.” Because I knew, this was my starting point. There’s gotta be a way to stop this.

Clark described his guardian angel as involved in his positive, spiritual experience of awakening to his correct diagnosis, as well as the “starting point” of a long search for successful treatment. Reflecting back, he relied on his mechanical metaphors in which a “starting point” must identify the way to “stop this.” His spiritual tone continued as he reflected on his interaction with his family physician, in which he reportedly informed her of his misdiagnosis:

My family physician sat there when I went to see her after that, when I was gonna get my referral to neurology and she apologized. For ten minutes. Saying, “I’m so sorry I missed this.” And she was going on and on and on and she even explained that doctors don’t know everything and the whole mea culpa.

Again, he framed his experience spiritually describing her apology as “the whole mea culpa,” a formal acknowledgement of fault that would traditionally be cited in mass. Many people with epilepsy — throughout history and perhaps due to history — have made spiritual references in regards to their seizures and epilepsy (Temkin, 1994). For example, recent published narratives cite scripture and describe spiritual approaches to their illness (e.g., Curry, 2006; Kissing, 2003). This spiritual tone and commitment introduces a central theme in Clark’s narrative, in which he identified devoting his life to speaking about his epilepsy identity, almost as a point of awakening to his life’s purpose. He identified his spiritual goal as three-fold: to find his own cure, to support others with epilepsy, and to educate members of the public about epilepsy.

5.5.2 A saviour. *To Dr. Smith: I owe you my life. (Written narrative)*

Clark’s perspective on physicians seemed to shift over the course of his narrative, layered with frustration while he dealt with misdiagnoses. He expressed irritation at the arrogance shown by physicians who he feels are limited by the sheer fact that they are human and are simply working with what God has given them. It is noteworthy that these expectations are consistent with his conceptualization of physicians as “mechanics” and that despite his frustration he does not expect that they would be able to perform any better:

They’re not all-knowing. And, and I think that’s the biggest problem now with physicians is, they have to build themselves up so much to get there... they get their degree and they think “That’s it, I’m omniscient, omnipotent, and all that, and they’re not. They’re humans who are doing their God-given best to help people.

Clark’s perspective on the limitations of physicians seems to have shifted when he encountered a neurologist who he describes as a life-long friend, supporter, and saviour. Notably, he characterized this physician as possessing none of the powerful limitations that his other physicians possessed. Clark repeatedly attributed his survival to his neurologist, Dr. James Smith.

Playing a principal role in his scripted narrative, he has the specific memory of Dr. Smith taking his hand, and the two of them looking down on what would become his place of fellowship and worship:

That's why Smith was, you know, heads and shoulders above the crowd because he said:

"Come with me, grabbed my hand..." actually I remember him grabbing it because I said

"What are you doing?" and then he grabbed my shirt and he said "You see that?" ...

there's the 7th or 8th floor [of the hospital] and we looked out and down below there's two

little houses and down below that's where [the local organization for epilepsy] is. And he

said, "You see that door? That's where [the local organization for epilepsy] is." I think

he was head of the organization at the time but he sent me there.

This narrative passage is repeated throughout each of Clark's narrative pieces (i.e., video, written and oral narrative), likely highlight the significance of this event. Dr. Smith took his hand and led him — much in the way a spiritual guide might lead him, to a spot where the two of them looked down — the way that a God might show a disciple and look down on a humble space where average humans were going about their daily life.

Dr. Smith is portrayed as a saviour, as someone who — unlike the other physicians — was able to correctly identify Clark's illness. While Clark indicated that a medical student had established his initial diagnosis, Dr. Smith's validation of this diagnosis and appropriate treatment appeared to increase the level of trust between patient and physician. Clark further described his belief in Divine Intervention in leading to his encounter with Dr. Smith. Clark's faith in Dr. Smith presents beyond his belief in his abilities as a physician; he explained that Dr. Smith emphasized the importance of peer support, as well as the ability to validate the patient's experience because he *"knew the human side of epilepsy."*

Dr. Smith is perceived as allowing Clark to play the role of patient-as-expert as well as patient-as-friend. This appeared as a key element for Clark, who repeatedly indicated a need to feel knowledgeable and to feel validated, given his prior history of having his symptoms called into question. He introduced Dr. Smith as a peer, a friend who was nonetheless socially outranked by Clark in their University years. Whether or not this relationship was central in their younger years is unclear; however, he made it clear that he perceived his dynamic with Dr. Smith to be different, perhaps superior, to that of the traditional patient-physician relationship:

But that's the kind of relationship we had, we were friends first and patients... he never ever stepped around the doctor-patient, but he never missed a chance to let me know that he was in it with me.

Clark's statement implies that he believed in — or was aware of — a traditional doctor-patient relationship. He suggested that his relationship with Dr. Smith was out of the ordinary based on the fact that they were “friends first” and that “*he never missed a chance to let me know that he was in it with me.*” His descriptions of these characteristics indicate that he did not experience or expect these characteristics in other doctor-patient relationships. Clark openly described Smith as a saviour based on his depiction that, simply by looking at Clark, Smith knew that Clark was considering suicide and that he found him a solution by “*achieving the impossible*” and getting him in to the epilepsy surgery unit within 24 hours. While Clark described his experience in London as having saved his life, he did not fail to mention that it was Dr. Smith who led him to this place, nor did he neglect to mention the fact that the individuals working in London loved Dr. Smith. Clark portrayed Dr. Smith as being respected and praised by his peers, so much so that he is portrayed as all knowing and superior to them.

Despite Clark's conceptualization of his surgery as a mechanical process, he paired this with a spiritual description of both the surgery and the surgical recovery, perhaps indicating elements of certainty and uncertainty:

And I knew when I went in there that everything was going to be okay. I went in with complete faith and that, to this day and dealing with all the depression and all the crap that followed afterwards... Ya I get frustrated, I get angry but I knew, and heck I've gone through a divorce... I knew that God was with me. I don't believe in... I believe in God and Christian. But I don't believe that I have to go to church to have someone put their hand on my head.

5.5.3 A preacher: Captain Epilepsy. Clark repeatedly referred to himself as a “champion for the cause” by playing numerous roles in epilepsy community services. He described his own involvement in the local organization for epilepsy, in which he joined the Board of Directors shortly after his diagnosis, and was later hired on as a representative once the position became available. He described numerous dichotomous identities related to his level of power and perhaps perceived control. The minority of identities involved a sense of helplessness, a victim, and a shift from driver to passenger after his diagnosis. In the majority of his descriptions, however, he positioned himself on the opposite end as a survivor, one who has been empowered, and an “avenger” or superhero. He explained this shift best perhaps in his statement that he “champion’s the underdog,” demonstrating how he acknowledged the limitations that epilepsy can bring but that he chose to take on the cause and as such, empower himself both because of and despite his illness.

Then I put the cape on, right? Like, that’s where I, I became Mr. Ep- Mr. Epilepsy, because that’s where I said, “The only way I’m gonna beat this is if I become a champion

for the cause.” And I got all sorts of stuff, like, I dunno... it’s still here somewhere. Here. From [the local organization for] epilepsy]. It’s a thank you plaque... from 1994, for just... I had to become a champion for the cause. And I still have that to this day. Umm, so that’s my story. I do not hesitate for a second to tell my story.

While Clark never identified himself as a preacher per se, his identity as Mr. Epilepsy and Captain Epilepsy — as well as the roles that he takes on in various epilepsy organizations — suggest that he is a vocal supporter of the community. He recalled a conversation with his grandfather regarding his role in life, which provides insight into his past actions and current identification with the “preacher” persona:

My, my grandfather once told me... back, this was back in, uh... goodness knows when it was, umm, but he said, he had a dream that he saw me up preaching to people, preaching to the congregation... And then there was a point in my life where I realized that, as I was standing up there talking to people about epilepsy that my grandfather was watching out over me, saying, “That’s what I wanted you to do.”

Clark demonstrated what many people do in Frank’s (1995) illness quest narrative: he states that his epilepsy was an illness that he not only overcame but that also provided him with a sense of purpose in his life, in that he has become a messenger and a leader for others. In his own words, he was “preaching” albeit not in a religious sense. Instead he was standing up in front of individuals with epilepsy, as well as some without, and sharing with them information, messages, perhaps the faith involved in living with epilepsy. Clark described this religious conceptualization of epilepsy as a faith that he preaches:

I’m done. Basically, I’m seizure-free. I have little small partials sometimes. So I could just wash my hands and walk away. What the heck? What a waste, like, if I could tell one more person, and I say that just, you know... if I can tell one more person about epilepsy,

then that's one less person that has to know and I just... so if I can get in front of a group of 300 people and tell them about epilepsy, about my experience... let them know that I'm normal, then that's ya... that's pretty cool. And that's what I've done is I've taken this spirituality and I've put it out there. You know do I tell people... I can't sit in a room where people are going, "Praise the Lord!" It's not like that, and all that stuff. It's not like that, it's very personal, but I can talk to... "You wanna know about epilepsy? Well I can tell you about epilepsy..." and I'll sit down and you know, we'll talk about it.

In this quote, Clark appeared to illustrate his investment in epilepsy as an illness and his desire to speak about it. Given that epilepsy became an illness that dictated the way he lived his life for over 10 years, and continues to have a significant impact on him, I suspect that he is not able to “just wash [his] hands and walk away.” He indicated that his priority is to educate others about his illness, however, he also emphasized the need to “let them know that I’m normal.” This portrayal of normalcy may be to remove negative misconceptions, but there may be an element here of him needing to assert his own adequacy. Regardless, Clark illustrated his commitment to the cause with multiple ways in which, much like clergy, he supports both individuals and groups struggling to understand this illness and its role in their lives.

5.5.4 Fellowship: Summer camp and surgery. Clark repeatedly refers to the fellowship — or lack thereof — that he experienced with others who have epilepsy. His first described experience was his referral to the local organization for epilepsy, the building that Dr. Smith is watching over, where he was able to meet and support others with epilepsy. While this may have been his first interaction after being diagnosed, Clark did not describe hesitation or apprehension at these first meetings but rather excitement at meeting others with his condition. The most excitement he expressed about finding his peers involved his description of the hospital in

London, in which he met other individuals who were also undergoing surgical assessment and treatment for medically refractory seizures.

Clark: It was like summer camp for people with epilepsy. They take you there, they take you off your drugs and they want you to have seizures.

Me: Why is it like summer camp?

Clark: I made some of my best friends there. They've gone on. Lost touch with them. But at that time, there was nobody in my life closer to me than those people... I see summer camp as a place that you learn, that you enjoy, and fellowship, and... that's exactly what it was.

Clark became an even more animated storyteller in recalling his time in London, describing the epilepsy experiences of multiple friends and peers. He described bonding experiences in which he shared moments and personal events that had not been shared with anyone outside of the hospital. He described providing support for peers who were recovering from surgery, as well as receiving support from these peers both in hospital and while recovering at home.

Clark emphasized that the fellowship was unspoken and that the individuals supported, respected, and understood the needs of their peers based on their shared epilepsy experience. His terminology shifted while he recalled his experience, in that he began to refer to his peers as “members” emphasizing the “fellowship” of this shared experience. While the initial experience was of unclear barriers surrounding privacy and the seizure experience, his inspired reaction that there were no barriers and that this was a shared experience seemed to confirm for Clark the support of his peers:

I didn't go over right away because I didn't know what the barriers were, you know, if you... if I had a seizure, like, who do I want around me kind of thing. When I'm coming

out of it, umm... so, with this, Johnny, I wasn't sure what the protocol was with the hospital, I mean, there was a nurse beside him when he was coming out of it, they were monitoring him and everything... then I realized, somebody on the other side of the bed was one of the other members that had gone and sat with him, and then I realized this person was falling asleep in the chair and then I went over and said, "Here, let me sit for a while," and we rotated like that and it was, not organized, it just happened. And that's just the kind of thing, ya. It just, umm, London for me was... a love-in.

5.5.5 Preaching to the congregation. Clark identified that, *"different people with epilepsy deal with things in a different way."* This statement is not only helpful in establishing his awareness of the diverse reactions to an epilepsy diagnosis; it is also a helpful reminder of the contrast between his reaction and that of others. While he eagerly sought a diagnosis and proceeded to make it central to his identity, others may question their diagnosis and avoid identifying their epilepsy. Clark reinforced his experience with this reaction, describing others whom he has known: *"I think a lot of people who got out of [London], wanted to leave it behind and never go back."* Here he acknowledged a historical fact and ongoing reality that many individuals with epilepsy choose not to disclose their illness identity when their seizures are not visible or are medically controlled (Kilinc & Campbell, 2009; Scambler, 1993; Schneider & Conrad, 1990).

Despite his awareness of individual differences, Clark describes himself as a "militant" in strongly encouraging others to be more open about their epilepsy. In our conversation, he was critical of individuals who chose to keep their condition a secret. In comparing the disclosure of epilepsy with other illnesses, Clark describes an experience in which he was able to compare an individual's experience living with both HIV and epilepsy:

I... a lot of people when they find out they have epilepsy they don't want to talk about it, they want to put it behind them, you know, when I was working at [the local organization for epilepsy] I had this guy come in who really wanted some advice about how to deal with his epilepsy. And the guy had HIV. So... he came in and, this is, I get a little agitated about this... he came in, he had HIV, he was terrified that people were going to find out about his epilepsy. And I'm thinking, at the time, I said 15, 20 years ago, maybe 25 years ago, nobody had ever heard of AIDS and the world got behind it, and AIDS is now, millions, if not billions of people champion this cause. It's a health problem. It's a health issue. But within 30 years, the world is aware. You have to be living in a cave not to know about AIDS. And yet... I would say less than 15% of the people in the world know about epilepsy. AIDS has been around 30 years, epilepsy's been around... Caesar had seizures. So it's been around for centuries, and, millennia, it's been around for millennia, and still we're battling to get it recognized, you know we're battling to get understanding, research, and stuff like that... it just blows me away."

He expressed frustration, which might in part be a result of his own expressed difficulties in getting an accurate diagnosis and coping with public perceptions of treatment. In addition, he expressed frustration towards the individual who came in looking for support. In this context, it is worth considering that Clark may perceive a lack of understanding and a lack of progress, not only from researchers, clinicians, and society in general but also from his peers with epilepsy. His statement that individuals with epilepsy "*don't want to talk about it, they want to put it behind them...*" highlights the isolation that Clark may feel, in addition to a medical and societal system that he described as having let him down.

In *Illness as Metaphor* (1977), Sontag suggested a transition in illnesses that are popularized by society as the primary stigmatized illness, until a cure is found. She expressed

that, around the time of her diagnosis with cancer, it was the stigmatized and misunderstood illness around which negative metaphors lingered (Sontag, 1977). She later updated her perspective stating that AIDS had become the misunderstood and stigmatized illness (Sontag, 1988). Of interest to me is the fact that, as identified by Clark, Temkin (1994) has traced biomedical and societal conceptualizations of epilepsy throughout the millennia without observing the same de-stigmatization that Sontag might anticipate. Nonetheless, epilepsy never appeared to reach the mass awareness that Sontag described for cancer and AIDS. Further, Sontag (1988) clarified: “Diseases, insofar as they acquired meaning, were collective calamities, and judgments on a community. Only injuries and disabilities, not diseases, were thought of as individually merited” (p. 133). As such, it is possible that epilepsy would not be considered a disease, given that it is not contagious, deadly, nor impacting a community en masse, and as such would be considered a disability based on Sontag’s definition (1988). An alternate interpretation is that the epilepsy “community” has never reached the large number of individuals affected and, as the illness itself is only visible in some individuals during the seizure state, even the large number of individuals affected would be under-represented.

5.5.6 Preaching to the public. In multiple instances, Clark described his frustration with what he identifies as public ignorance regarding what epilepsy is and how it presents differently in different individuals. In one statement of trying to get the public to “buy into it,” we hear the echo of his “preacher” role. Similar to his past experiences of trying to convince physicians that his seizures were not “mystical” but rather “real” neurological experiences, he appeared to attempt to de-mystify epilepsy and convince the public that the illness is not based on possible societal misconceptions:

It's just the fact that... it's this incredible health issue that you just can't get people to, you know, you can get some people to buy into. You know, they... "Epilepsy? Oh, that's where you fall down, you know and all that, and everything else."

Clark expressed frustration at parents and physicians who encourage those with epilepsy not to disclose their illness and explained that more individuals are needed to “get on the bandwagon” in order to increase public awareness and support. In a reflection on Sontag’s commentary (1988), he seemed to be arguing a desire and a need for epilepsy to be considered as a disease, impacting a collective, rather than as a disability that impacts an individual. He explained that, until epilepsy became a cause that had been taken on by a larger group or famous individual, it was up to him and other families impacted by epilepsy to educate the public. Acting on this perspective, Clark provided public education sessions for students and community members where he introduced medical terminology (largely through mechanical analogies), told his personal narratives, and re-enacted “fake” seizures to demonstrate what individuals might witness.

Despite the stress that he portrayed in living with seizures, Clark illustrated the way in which these seizures had become so central to his identity that he continues to re-enact them rather than avoid them or try to put them behind him. It appeared that he was attempting to instil a sense of safety surrounding seizures, despite the fearful and dramatic descriptions that he himself described in our conversation. Clark illustrated for me the way in which he attempted to demonstrate seizures, wanting medical students to learn that seizures can be “easy,” and may occur without visible indicators. He described a re-enactment of a seizure from which he jumped at the crowd and yelled: “*Gotcha!*” This type of behaviour suggested to me both a sense of humour and a sense of pride in no longer feeling controlled by his seizures. Regardless of his past experiences and ongoing re-enactments, Clark has become an ambassador and rather than walk

away from the seizure experience, he appears to hold on to it even after his seizures have, by his description, become relatively controlled.

Clark described his move to Saskatoon as a difficult adjustment, partially based on the lack of public awareness of the illness. He explained that, in order to meet individuals, he started by telling his story of epilepsy. Once he experienced acceptance and support with his story, he felt validated and continued to the point that he was encouraged to give a keynote speech at a large public gathering. Here, he expressed personal conflict, as he was unsure whether to be open about his epilepsy or whether this might betray his peers who were still conflicted and afraid to share their stories. This leads us back to one of Clark's own statements regarding his role as Captain Epilepsy: *"I don't want to be Captain Epilepsy all the time, but if they need somebody to step out of the phone booth, I'll be there."* Here he seemed to contradict himself in that he confidently stated no hesitation to tell his story, but then indicated a desire to limit his identity as Captain Epilepsy.

Clark's interesting use of metaphor in reference to *"stepping out of the phone booth"* portrays him as a "normal" human without a known or visible illness, but who has the superpowers of storytelling and moral support that he is willing to share when needed. Alternatively, this could fit with the more common passing as an individual without epilepsy, with disclosure of his illness only as needed (Kilinç & Campbell, 2009; Kirchglässer, 1990). Clark indicated a preference for moments where he could choose to be visible, such as wearing an epilepsy fundraiser t-shirt to gain awareness at a rally. In contrast, he described the embarrassment of permanent visible marks on his face that are the result of one of his medication trials, and expressed that this limited his ability to be invisible.

5.5.7 Empowerment: Sacrifices made. As Clark's narrative introduced transitions in his identity that centred on epilepsy, he noted a particularly challenging shift from someone who was

in charge to someone who was dependent on others. In attempting to integrate his illness identity, I perceived him shifting the way in which he maintains a sense of power and control, requiring sacrifices that came with this new identity. His description of diagnosis after his first tonic clonic seizure was helpful in portraying the significant shift that took place in his role as a father.

Me: You described being diagnosed and you said that the doctor came in and said: “You had a grand mal seizure and you cannot drive for one year.” And you heard nothing else.

Clark: That’s right.

Me: It was interesting to me that those were the 2 things that you heard... and I’m wondering about the significance.

Clark: My third daughter was three months away. It was my daughter’s... March 21st, the reason I remember it is because it was my second daughter’s birthday. So here I am, young father of 3. How am I gonna get them, how am I going to get my wife to the hospital when the baby’s born? Why am I, how am I, what am I going to do? And everything. My whole world was crashing down. How can I work? How can I... I didn’t think of the solution... Because once you lose your license, you become a passenger. So it was, ya, it was difficult. It was a kick to my self-esteem, my manhood, everything like, I did all the driving- you know what I mean? It was just, you know... it was tough.

Here, Clark appeared to demonstrate the central role that epilepsy had on his role in the family. His description of a shift from “driver to passenger” perhaps best illustrates the immediate impact of his diagnosis, and may suggest what may have become an increased need to demonstrate control and dominance in other aspects of his life. Clark’s emphasis on the importance of having a driver’s license as a demonstration of independence reflects a struggle frequently described by individuals with epilepsy, one that plays such a central role in adjustment

to epilepsy that the adapted Quality of Life in Epilepsy questionnaire (QOLIE-89; Devinsky et al., 1995) created a separate subsection for this aspect of identity (i.e., “Driving”). Not only did Clark’s initial experience illustrate an immediate impact on identity beyond the medical symptoms (e.g., “you lose your license”), but it also indicated a broader step back in the traditional developmental role that one might take (e.g., “you become a passenger”). Clark emphasized the way that this statement stunned him and immediately had him contemplating if and how he would be able to transition from a role as a patriarch but also as the dominant partner in his family, explaining that his wife did not have her driver’s license. This appeared to carry both factual and symbolic meaning, as he expressed significant dismay at having to not only lose this role but also become dependent on his partner. As he stated: *“I went from being head of my family to being a burden on my family.”*

In all narrative accounts provided, he described his “single worst experience” as having a seizure in front of his daughters:

I was standing at a bus stop with my two daughters and they looked up at me and they looked scared. Can you imagine how you feel when you realize you can’t be left alone with your kids... you know?

This description begins with a positive and memorable father-daughter experience of taking his girls out to a hockey game. It does not seem coincidental that the memory includes a moment where the family was standing at the bus stop, highlighting again the fact that Clark was unable to drive his daughters home. He stated: *“Nothing else could be done to make me feel worse or less of a human.”* Clark described this as a pivotal moment that caused him to seek, out of desperation, whatever final treatment would heal him of his epilepsy. In the narratives he shared with me, Clark attributed the end of his marriage, his limited contact with his daughters, and his choice to move away from the family as choices that he made to protect his family from

his epilepsy. He seemed to identify himself as inseparable from his neurological state, including both his epilepsy and the later consequences of his surgery, and thus he seemed to conclude that the only way to remove the burden from the life of his family was to remove himself. He seemed to position himself in the role of the martyr, by sacrificing himself and his happiness when he chose to leave his wife and “did her a tremendous favour.” This reframed his experience in the sense that he seemed able to reclaim control, a role of the dominant partner, while also illustrating a sacrifice made for the good of his family.

His initial shift from a dominant role in the family was paralleled by his experience in the workplace. Not only did this continue his shift from a dominant role in his family, as primary breadwinner, but it also portrayed punishment in both social and employment roles at his workplace. Clark appeared to perceive betrayal from an employer he had worked for “*all of [his] adult life*” when he lost his management status in front of his colleagues. He dramatically tied together the loss of his driver’s license with this loss of status: “*Then when I lost my [driver’s] license they said, “Well, we’ll take your keys away cause we don’t want to come in and find you at the bottom of the escalator because you had a seizure.”*

By taking away Clark’s keys, he was demoted in terms of his level of responsibility and the action of having to hand over his keys provides a concrete action, reminder of this demotion, and illustration of workplace attitudes (Jacoby et al., 2004). He described having a complex partial seizure in the boardroom after which he heard his colleagues laughing at his disorientation. He expressed a feeling of betrayal and mistreatment from others in the workplace, perhaps worse than his formal demotion. Clark explained that his leave from his company enabled him to take on the role of Executive Director at his local epilepsy organization, again demonstrating empowerment and pride his ability to reclaim a leadership role, as well as further his service to the epilepsy community. At the time that I encountered Clark and heard his

narrative, I encountered an individual who had seemingly reframed his life around his epilepsy with a past identity characterized by sacrificed family and occupational roles, and the development of a new identity involving roles that are both empowering and compatible with his illness (Charmaz, 1997).

5.6 Conclusion: Finding the Winning Team

During our conversation, Clark brought up his father as a role model on how to live with illness. Despite Clark's repeated use of battle metaphors in reference to his epilepsy (e.g., "war wounds," "gone into battle," "fight it"), he stated that these were more accurately used in cancer narratives. In explaining this contrast, he discussed his father who had recently passed away from prostate cancer:

They can fight cancer. If you're terminal, you know, and my dad had heart disease, and he knew he was terminal. And he settled all accounts. When he had prostate cancer, he started then settling all accounts so he could adjust to it. With epilepsy... (pause)... it's just, I think the worst part is, you don't know... if or when it will end. It's just, and you just have to continue to live life.

Here it was of interest to me that Clark perceived the primary benefit for those living with cancer as opposed to epilepsy was not that "they can fight it," but rather that they did not have to live with uncertainty. He expressed that, from his perspective, the worst part of living with epilepsy was the uncertainty of having to live life indefinitely and without being able to "*settle accounts*." This seems to fit with Sontag's (1977) reference to meaning making of great illnesses as centred around existentialist questions of impending death. In contrast, a central piece to Kleinman's (1988) definition of chronic illness is the uncertainty of a life with fluctuating symptoms. As discussed, Sontag defined illness as fatal epidemics that impact large communities (e.g.,

tuberculosis, cancer, AIDS), as opposed to her description of disabilities, which may more accurately capture epilepsy given that it is seen as impacting individuals (Sontag, 1988). While she theorized that the social stigma impacting these illness communities would subside as the illness itself becomes better understood and de-mythicized, this may or may not be less accurate for chronic illness or disability, as she identified these as “individually merited.” Sontag’s portrayal here fits with Clark’s portrayal of an individual entering into a team sport, much like a battle, without any teammates.

Clark: *Epilepsy isn’t like a war or a battle. Because cancer is a war or battle and immediately, as soon as you are diagnosed you are part of one of the greatest armies ever known to mankind, or humankind. But... epilepsy, when you’re diagnosed, all of a sudden, the NHL draft is over and you’re on the crappiest team. They don’t even know who you’re going to be playing. They don’t know what the name of your team is. And that’s my first sports metaphor, or sports analogy, whatever.*

Me: *Um-hmm.*

Clark: *It’s just, the fact, that’s what epilepsy is like. You’re just, you feel like you’re on a losing team and really, you don’t have a coach, unless you go looking for it. Like, it’s... do you have any idea how many people are diagnosed- well, I’m sure you do (laughter)-*

Me: *Tell me.*

Clark: *But people with epilepsy are diagnosed by their family physician and they’re not referred to the epilepsy organizations, they’re not referred to a neurologist. Here, take this, and the family physician is just gonna give ‘em something. I’m sorry, but even if they give them something and it stops the seizures, that person still needs support. You know, why all of a sudden after 5 years do I have another seizure? Why all of a sudden am I taking all this medication and gaining 30 or 40 pounds? Why can’t I get out of bed?*

Why can't I hold a job? Why can't- you know, and all these other things. So there you go- you've got your losing team. Until you get a winning team.

After Clark described his father's struggle with cancer, I asked how he experienced his own illness. That is, how might it be the same or different from his father's experience? As noted above, he differentiated between cancer as an illness in which you are part of one of the "greatest armies," as opposed to epilepsy as being chosen for "the crappiest team." Clark's reference to cancer being "one of the greatest armies" may seem counterintuitive given the prognosis for a terminal cancer patient. However, it could appear that he was less focused on illness prognosis and more focused on the fellowship and support from the public, peers, and health care community. In describing epilepsy as the "losing team, don't even know the name of the team, no coach," he takes us back to the uncertainty he experienced living with an illness that was initially misdiagnosed and unsuccessfully treated. Further, the relative anonymity and misunderstandings that he identified regarding epilepsy in the public eye appear to impact his perception that one is alone, without a coach, "until you find a winning team." Clark's portrayal seemed to summarize his experience of feeling misunderstood and struggling to understand his illness experience, as misdiagnosed by the "mechanics."

His coach or saviour, Dr. Smith, as well as the fellowship of his peers with epilepsy, indicate his characteristics of a winning team, a team that gave him successful treatment and support. For him, it appeared that it was not the condition necessarily but the biomedical and social misunderstandings that initially defined his losing team. Thus, Clark's shift from losing to winning team involved finding his saviour, his fellowship, and ultimately the empowered narrative identity that he created for himself. Perhaps a final indicator of Clark's perception of having overcome epilepsy, portraying himself as an epilepsy advocate rather than a patient, is the following statement: *"I am over the boards if there is a need for epilepsy wrongs to be righted."*

From Clark's narratives, he seems to identify as one who has gone into battle, survived, and is willing to return should his teammates find themselves fighting. While Clark's peers may have overcome epilepsy and chosen to move on with their identity, he has committed himself to living both with and for epilepsy.

Clark framed his seizure experience and epilepsy experience as central to his identity, first due to the disruption that they caused and then for the powerful role that they play in enabling him to overcome his illness and achieve a higher purpose. Clark identified many peers who he believed would rather forget about their epilepsy after having successful surgery. In regards to his epilepsy, Clark states: *"I'm done. Basically, I'm seizure-free. I have little small partials sometimes. So I could just wash my hands and walk away."* While Clark identified a need to continue educating others and identifying as Captain Epilepsy, Cam, who we will meet in the following chapter, chose the route of re-defining himself in what seem to be "anti-epilepsy" identities. While both of these men have undergone surgery for their epilepsy and have experienced significant identity transitions along with their treatments, the identities they define are vastly different. Let us now consider Cam's approach.

CHAPTER SIX

Cam: Epilepsy and Time

6.1 Meet Cam

Cam became aware of my study when I presented my research poster at the Annual General Meeting for the local organization for epilepsy in April 2011. After the presentation, he expressed interest in sharing his narrative. I had known him through the local organization for epilepsy as a very upbeat though soft-spoken individual. He was a single man in his early 40s who lived on his own and, though he discussed his relationships with family and friends, it was evident that he took pride in his independence. Within a few days of our initial conversation, Cam emailed me his written narrative entitled: “*My Life with Epilepsy.*” In it, he focused on his philosophy of life as it related to his attempts to prevent epilepsy from impacting his everyday, particularly his relationships and his career. He described gradually feeling overcome by his illness and left a warning at the end of his piece: “*After twenty years of dealing with Epilepsy, my final synopsis would be that less optimism equals less frustration.*” Something that struck me in Cam’s writing was his use of a capital “E” every time he mentioned “Epilepsy.” This distinction suggested to me the powerful role that Epilepsy played in Cam’s life, and it was one of many elements that I noted for further discussion when I met Cam in person. I have also used this capitalization when describing the separate “Epilepsy” identity that Cam portrays in his narratives.

A week later we met in an interview room on the university campus. I remember thinking that he seemed more positive but also more guarded than he had presented himself in his written narrative. His statements were often punctuated with nervous laughter, which was often

incongruent with the seemingly confident statements he made about himself and his Epilepsy. Cam's focus in his written narrative was on his emotional adjustment over the course of his illness; it read as a reflective and thoughtful piece on emotional transitions. When Cam began speaking in our interview, he made little mention of emotions and instead introduced a chronology of seizure activity, diagnostic labels, medications and medical treatments, with functional explanations of how these medical experiences had impacted him over time.

Cam explained that at age 26, almost 20 years prior to our conversations, he had experienced his first seizures and was quickly diagnosed with “complex partial seizures” and “epilepsy.” After his diagnosis, Cam identified being on anticonvulsant medication for a period of about 10 years before he began experiencing seizures again. He described how he had then undergone surgery after his seizures had failed to respond to medications. In our discussion, he considered how the epilepsy label had made its way in and out of his life, in part dictated by his conversations with different neurologists. My reflections on both his written and oral narratives were that Cam felt more comfortable discussing epilepsy in more formal medical terms; perhaps because this is what he had been taught to do, perhaps because he was better able to distance himself from the illness and its impact on him when he focused more so on symptoms than on emotional implications. I considered it a real honour to have met Cam in two very different spaces; his written and oral narratives together provided me with a much richer perspective on his experiences. We will now reflect on Cam's narratives and the primary theme of medical labels as signposts along his journey, also seen as “timemarkers” and “turning points” for Cam as he has lived with Epilepsy.

6.2 Cam and Time: Past, Present, and Future

Cam's narratives are characterized by references to time with several narrative pieces that seemed driven by a conflict between two main characters (i.e., Cam himself and his illness, Epilepsy) from the occurrence of his first seizure to the present day. In a section from his written narrative below, Cam shares a retrospective consideration of his epilepsy experiences over time:

After close to twenty years since being diagnosed, most of my naiveté and optimism has become a thing of the past and has been replaced with a necessary acceptance of the issues that I experience as simply the way things are. Knowing that I can't change what has happened and knowing that the future is something I shouldn't worry about does eliminate some of the frustration and some of the worry and sorrow. (Written narrative)

Cam differentiated his own identities based on time and stage of illness, but he did not identify his Self as the identity that had changed, per se. That is, he frequently referred to "Cam" in third person, adding descriptors to clarify which version of "Cam" he was referring to over time. He referred to "Cam" in third person as his Self prior to Epilepsy. After his seizures were identified he became "Consistent Cam," an identity that prioritized his ability to maintain consistent function despite his Epilepsy. He later described "different Cam" after the source of his Epilepsy was surgically removed, and as he adjusted to his medication side effects. He finally indicated that he was "back to the old Cam" after surgery, reduced medications and, according to him, without Epilepsy. In his present day, Cam identified as someone who no longer had Epilepsy but may have the chance of "non-epileptic seizures."

Cam's final characterization of returning to the "old Cam" highlighted the way in which his narrative was scripted retrospectively, with his stages of illness and Self serving as significant signposts in a linear illness chronology (Charmaz, 1991; Kleinman, 1988). Given Cam's

emphasis on overcoming Epilepsy, his narrative had likely been re-shaped with these stages considered as “turning points,” as defined by Charmaz (1991): “not only does a shift in direction result, but also a shift in self follows” (p. 197). I was left pondering which Cam was I speaking to. By presenting himself as an observer and later, as a survivor, throughout his retrospective description of his illness, I was speaking to an individual who had distanced himself from the illness experience and the illness identity itself. Cam emphasized his positive relationships based largely on those in his life that are willing to ignore any indication that he “had” an illness. Revisiting Cam’s “turning points” in his written and oral narratives provided me with an opportunity to better understand Cam. It also gave me insight into the significant roles that diagnostic labels and time can have on the life of the individual with a seemingly static “Epilepsy” diagnosis.

6.3 Cam’s Seizure Narrative: “Before and After Was Just a Continuum”

When asked to “*tell me about [his] experience with epilepsy,*” Cam began with a traditional biomedical narrative trajectory of his illness, including his first witnessed seizure, his diagnosis, and his treatment (Charon, 2006). This provided a helpful overview of his experience with epilepsy that introduced me to the main themes of his narrative:

Cam: Okay, well, actually I think I was fortunate in, ah, I had my first known seizure in front of a nurse. I was working, doing some computer work for the Victorian Order of Nurses and I was sitting at the computer and updating a database that they had and trying to show her where her input thing would be, and we were moving from a flat file database to an original database, so there would be a lot less inputting. And I was trying to explain all of this. So, at some point in the process, of course unknown to me, um, she tapped me on the shoulder and she said, “Did you know you just had a seizure?”

Me: *Mm-hmm.*

Cam: *So... naïvely me, I mean the only thing I knew about seizures, and I mean epilepsy in itself, is the violent thrashing on the floor, possible injuring yourself kind of thing. And here I am still sitting in this position, ready to continue typing.*

Me: *Ya.*

Cam: *So... it wasn't like I disregarded what she said. I mean, I understood in her medical opinion, I must have had a seizure, right?*

Me: *Ya.*

Cam: *To me personally, I wasn't really aware that I had had a seizure. So, beginning before and after was just a continuum to me.*

Cam's seizure narrative was a helpful introduction to his initial conceptualization of Epilepsy. First, he reflected on his early self, an "innocent" and "naïve" Cam who was unaware of his own seizure occurrence, because it did not fit with his understanding of seizures or Epilepsy. He described how rather than the "thrashing on the floor" that he understood to be seizures and Epilepsy, his seizures were minor events based on time (i.e., "very short"), physical health (i.e., "never injured myself"), and visibility (e.g., an onlooker might only "notice a bit of odd behaviour"). Cam's professed innocence when his first seizure occurred and the uninterrupted "continuum" that he experienced portray the possibility, and to a certain extent his own reality, that Epilepsy might not even exist (or have existed) in his life.

Cam later explained that he was fortunate to have a nurse witness his first seizure, as she was able to give "it" a name (i.e., a complex partial seizure). Cam's first seizure involved scepticism regarding the actual occurrence of a seizure, though he explained that the nurse was entitled to her "medical opinion." This introduced a theme of Cam's negotiation of his medical labels, in which he prioritized medical authority when it fit with his preferred early

conceptualizations of epilepsy (Schneider, 1988). Cam described each medical label as it was provided to him by medical professionals, and used these labels as tools to frame his identity and his experiences over time. He demonstrated how the labelling of his seizures, epilepsy, and medications provided a sense of security, as well as served as a tool for him to communicate these experiences to others, emphasizing a role for medical authority and legitimization of his behaviour (Charon, 2006; Good, 1994; Schneider, 1988). The medicalization of this illness also provided a role for treatment (i.e., medication and surgery) to be separated and portrayed as a culprit for interrupted life and behaviours (Charmaz, 1991).

Medical labels not only provided Cam with a sense of legitimization, they also serve as signposts that enabled Cam to separate his illness experiences from his own identity. By labelling what his Epilepsy was and when it began, he was not left to search for words to communicate his experience to others. Instead, he found words to communicate who Cam *was*, as a reaction to describe what Epilepsy *was not*. He repeatedly identified the most prominent theme for himself: consistency over time. He explained: *“beginning before and after was just a continuum to me.”* He emphasized that he was able to continue on with his immediate actions, his day-to-day routine, and with his long-term *“plan as usual.”* By making this distinction, Cam defined both himself- Consistent Cam — and the illness that was external to him — (Inconsistent) Epilepsy. Cam’s emphasis suggested that, by maintaining a consistent identity, he might not draw attention nor need to acknowledge this medical condition. These portrayals are consistent with those held by many individuals shortly after their epilepsy diagnosis (Velissaris et al., 2007); however, as demonstrated over the course of Cam’s narrative, this perspective can be confronted when ongoing epilepsy-related challenges continue over time (Wilson, Bladin, Saling, & Pattison, 2005).

6.4 The Original Cam: First Impressions

Cam repeatedly highlighted that he was “innocent” by emphasizing his lack of presence in the seizure experience, and his lack of awareness of the seizures that occurred. He was an individual whose seizures were unnoticeable moments to Cam himself, and often to observers. In many instances, he took his “naïvety” a step further to imply that, by not being aware of his seizures, it may be possible that they did not happen at all:

Cam: Part of the reason that I mention that naïvety is that I noticed that it could have been a lot worse. You know, my first impression of seizures and of epilepsy... “Did I really have a seizure? I didn’t really feel anything.” I had a- déjà vu was initial, my initial feeling.

Me: Okay.

Cam: And we’ve all had déjà vu right?

Me: So what was that like for you?

Cam: It was feeling like I’d been there before, witnessed the same activity, and it was like, ha, a big chill down your spine while you’re feeling like you’ve just gone through a repetitive, something again, right?

Me: Mm-hmm.

Cam: And again, it was short-lived, the seizure happened right after and barely a minute long, and some repetitive action- and the repetitive action, I didn’t initially question the nurse. I wish I had at the time, to see if it was a particular hand or to see if it was a particular type of movement but, I mean, she just tapped me on the shoulder and she said what she said and you know, it was a complex partial. Okay. (Laugh). And so, um, again I wasn’t aware, it meant nothing to me, to my existence so uh, for the most part, it didn’t really affect me in any way actually.

In his description of his first seizure, Cam seemed to attribute his lack of seizure awareness to his own naïvety about epilepsy, explaining that his experience did not resemble his understanding of what a seizure was. In part, he attributed this to his preconceived and historically based notion of what an epileptic seizure looks like, which he described as injurious “violent thrashing on the floor.” He reasoned that, in contrast, his seizures involved minimal movement, were brief, and did not impact his behaviour apart from a brief lack of awareness. In doing this, he normalized his seizures and suggested that he could not be certain if, let alone how often, they might be occurring. Cam explained that, given his lack of awareness at the time of the seizure and the null impact on his behaviour, these seizures meant nothing to him or his existence – an interpretive move that could be seen as part of a major effort by Cam to normalize life, from life with Epilepsy as a character, to living with epilepsy as illness.

Cam further normalized these occurrences by comparing them to experiences that every individual has. While *déjà vu* is an experience that has frequently been associated with seizures in some individuals (Freeman, Vining, & Pillas, 2002; Sacks, 2012), Cam reframed it as an experience that all individuals have and looked for reassurance of this common experience when describing it in his narrative: “*we’ve all had déjà vu right?*” When he elaborated on the physiological process underlying *déjà vu* and his seizures, Cam normalized the process stating: “*technically it’s a misfire*” with the difference that for some people, the *déjà vu* does not result in a seizure. With the phrasing “*... you know, misfires can happen,*” Cam again provided a normalizing statement that misfires, just like mistakes, can happen, suggesting that this process should not be considered abnormal.

Finally, Cam provided a majority of occasions in which others informed him that he had experienced a seizure but that he himself questioned whether a seizure had occurred. These

descriptions allowed him to separate the Self from the seizure experience, suggesting that he was not at all involved in the seizure experience:

I was having déjà vu but- did every déjà vu have a seizure following it? Or did I have a seizure without déjà vu? I didn't know because they were complex partials, I was completely... gone. That minute that was missing... you know, I didn't stare at a clock to see that a minute had gone by or anything, you know?

Cam's statement: "*I was completely... gone*" powerfully communicates his experience; he equivocated his own lack of seizure awareness as a lack of his own presence. It was as though Cam stepped out of the room while others observed a seizure (Epilepsy), then Cam returned and was able to continue on with what he was doing. He explained that he relied on others' reports to know whether or not a seizure has occurred, given that he himself could not know this. His lack of conscious presence being equivocated as lack of illness was illustrated at its extreme when he explained to me that he could not "add or negate to the statistic" of individuals with seizures, in a research report that he described to me. Ultimately, Cam concludes that these seizures do not play a role in his life, as they are not in fact part of his life at all. In a review of epilepsy cases, Sacks (2012) reports similar reactions from patients who experience very brief seizures.

6.5 Cam and Epilepsy: The Medical Opinion

Cam began his narrative with his description of a seizure being observed and named by a nurse as a "complex partial" seizure, and he explained that he was comfortable because "it" had a name. Cam stated that he "*respects the nurse's medical opinion*" but again spoke of it in such a way that it might be called into question, given that it does not fit with his understanding of a typical seizure presentation. When asked to elaborate on how he was diagnosed, Cam maintained a passive role in the illness experience and diagnosis: "*I was sitting in the back row... And, uh,*

the next thing I know I'm being told that I might be an epileptic because I just had another seizure.” When asked to elaborate, he provided a medical definition for this diagnosis consistent with current medical definitions (e.g., Angus-Leppon & Parsson, 2008), demonstrating a formal awareness of epilepsy, though still not presenting his own opinion of the illness: *“the nurse had witnessed two seizures... her impression was that I was, should be classified as an epileptic... if you witness more than one [seizure] it's typically examined...”* The way in which Cam described the labels assigned to his epilepsy experiences (e.g., witness, seizures, epileptic), along with his capitalization of Epilepsy in his written narrative, created a narrative in which Epilepsy appears to become personified and separated from Cam himself, as an entity or individual who entered Cam's life uninvited.

Cam told his narrative in such a way that the majority of the labels he referred to were, from his perspective, placed upon him. He introduced each label (usually a biomedical diagnosis) that was placed upon him by a medical professional, and then explained how he made sense of it or researched its meaning. Regardless of whether he agreed or disagreed, and perhaps most importantly for treatment implications, regardless of his understanding of the labels, his interpretation of these labels framed his illness experience. As described with his early seizures, he occasionally remained skeptical and held a label at a distance, explaining that others (e.g., nurses, neurologists, employers) were the experts, but he ultimately utilized the label in the way that it worked for him. This was an interesting development of his illness identity, as Cam was able to organize his experience through the security of formal medical labels, whether or not they are accurately used in the biomedical sense. Kirmayer (2000, 2004) has previously identified such evolutions of the illness identity, in which individuals use their own interpretations of medical terminology to attribute medical authority to their experience.

6.6 Consistent Cam: An Anti-Epilepsy Identity

Perhaps the most interesting terminology that Cam uses was not a metaphor related to his Epilepsy, but instead Cam's terminology for his Self. He defined and repeatedly referred to Consistent Cam in what appeared to be an attempt to distinguish his Self from the feature that defined his Epilepsy: inconsistency. Here, Cam created an anti-Epilepsy identity, a Self that is distinctly different from the illness with which he was living. Consistent Cam uses time-focused terms such as "*continuity*," "*constant*," and "*blip-in-time*" to describe his steady level of function immediately before and after seizures, as well as after his diagnosis.

In exploring a piece from his written narrative, Cam explained that, during the initial ten years of his seizures, he experienced minimal interruption to his Consistent Cam identity:

Me: *Something else that I was interested in was the comment that: "Epilepsy wasn't holding you back/"*

Cam: */Ya I/*

Me: *"/initially."*

Cam: *Initially, ya. Because I was the same before and after. I could follow, you know, I didn't have to backtrack... in any way. Where I was at before, I could continue on right after. There was that however length of, you know, blip in time, um, (laugh) basically meant nothing to me. Because it didn't affect my before and after... in any way. That was during the complex partials so... I really thought that epilepsy, really, was nothing to me at that stage.*

Cam noted both the minimal duration of his symptoms, as well as the fact that he performed reliably on the job, as well as a friend and family member who did not do anything out of the ordinary. His focus on time before, during, and after symptoms, as well as the duration of time of the stages in which his symptoms were more controlled, is consistent with an individual retrospectively noting a steady state timemarker (Charmaz, 1991). Cam's initial interpretation of

Epilepsy as an uninvited but temporary interruption to his timeline was further supported in his attempt to continue with his planned lifecourse, and his described attempt to keep epilepsy separate from his life as usual: *“I didn’t have any adverse effects and again, I just went back to the plan I had without really even looking at epilepsy as part of my existence.”*

6.6.1 Consistent Cam: Social interactions. Cam’s formal labels and knowledge of Epilepsy provided him with the confidence to be knowledgeable about what was occurring, although he emphasized a desire not to delve too far into what epilepsy or his seizures entailed. In the similar way that his seizures were described as a non-disruptive “blip-in-time,” his social interactions could also be characterized as a “Consistent Cam” in that he described accurate yet brief explanations to those who witnessed his seizures:

Ya, I was totally, I had all sorts of confidence... then. I felt that, because it didn’t impact my before and after, and I was productive in conversation, in relationships, on the job... it really meant nothing to me other than... it might be something that someone could witness and, and I would just... explain it. And not dwell on it, like I didn’t want to go into huge details.

In terms of Cam’s social identity, I noted two important tensions between him and his Epilepsy. A common theme in narratives of illness identity, particularly in those where individuals describe perceived stigma, is the possibility that this impact is felt more strongly when it is perceived to impact the individual’s social identity. *“I didn’t want to have Epilepsy be... you know, talked about as being something that was a problem.”* This both emphasizes the way in which he continued to externalize this element of his experience, but also how he perceived it as an accompanying identity to keep hidden or distanced from his Self. Rätty and colleagues (2009) identified this conceptualization as consistent with those who defined epilepsy

primarily as a psychosocial handicap, consistent with Cam's primary focus on his lost social relationships. Similar to his seizure descriptions as "brief" and allowing him to perform continuous behaviour before and after, Cam also described his preferred conversations regarding Epilepsy as brief and allowing him to move on with his life. When asked about these interactions, Cam emphasized that both his family and friends demonstrated their support by keeping conversations about Epilepsy minimal. He further portrayed himself as owning and managing these situations, explaining his response to anyone who did inquire about possible seizure activity: *"I hardly ever told anybody that it was complex partial seizures, I just said, "You probably witnessed a seizure."* Consistent with Schneider and Conrad's (1980) early distinction of information management as "functional sharing," as well as Kiliç and Campbell's updated version of sharing one's diagnosis and healthy adaptation, this approach illustrates Cam's minimal acceptance of the condition while still enabling him to carry medical authority if he must address or acknowledge his illness.

6.6.2 Consistent Cam: Workplace. In terms of his work identity, he emphasizes how "Consistent Cam" is able to continue functioning at the same level and doing the same task before and after a seizure: *"prior to the seizure and after the seizure, I performed the same function I already knew without impairment."* This element of his identity, perhaps more than any other, is Cam's ultimate proof that epilepsy is not impacting his identity and, later in his narrative, his ultimate frustration when he notes what elements of his illness have been most disruptive to his life. In his descriptions of himself at work, Cam portrays his consistency, reliability and a sense of stability that were central to his identity:

I came there with a certain, expectations, and I had those expectations obviously before and after a seizure. So as long as that continued, I never had the impression that my, my

epilepsy was even an idea in anyone's mind, as long as I maintained that, you know, expectations that were set for me it really didn't play a role, you know.

Based on our discussion, Cam had always been an individual who was able to maintain consistent performance at the workplace and in life, though this consistency appeared to receive greater emphasis as Cam reflected on his life before he began experiencing seizures, as well as before his seizures became more disruptive. He described the first time that other individuals addressed concerns related to the impact of his inconsistent performance in work and social circumstances:

You're scratching your head, trying to figure out... why? Ya, that's not my normal... process. Right? And again, as I pointed out, you know, it's that consistency thing. I created a, a consistent Cam, you know, in their eyes and my eyes and my friends and then all of a sudden... something. Was notably not consistent. Because I didn't have an answer. I really didn't know... why I... wasn't that consistent person that everybody had this picture- even myself- had this picture.

Cam's turn inward and recognition of a Self that was different than the "picture" that he held indicated for me the centrality of consistency in his narrative. His reports of his first observed and treated seizures approximately ten years prior seemed to be positioned as an unwelcome interruption in his timeline, albeit an interruption that was minimal and that did not prevent him from getting back to the life he had planned. This initial experience suggested a timemarker or even turning point that he was able to minimize and accommodate without much social attention (Charmaz, 1991; Frank, 2010). It appeared as though Cam's consistency became something of which he was more aware after his diagnosis; however, it was unclear to what extent he valued this element of his identity prior to it being threatened by his illness.

Nonetheless, it seemed to become the focus for his attempts to demonstrate an ability to maintain his social and occupational identity. In contrast, Cam's identification of a moment in which he

was all of a sudden inconsistent indicated an “identifying moment” that challenged his self-image and lifecourse (Charmaz, 1991). Such a moment has been characterized by Charmaz (1991) as a “turning point,” as Cam expressed an emotional “loss of control” and “loss of identity within the events that spreads to an identifying crisis that lasts” (p. 218). Indeed, Cam continued to display confusion and insistence that this moment was the one in which Epilepsy took over his identity.

6.7 Medicated Cam

Cam seemed to make it clear that he respected medical professionals and medical authority, though he demonstrated conflicting emotions about his medical treatment. It is interesting to consider his conflict; he seemed to emphasize trust for medical authority and attempted to rationalize rather than challenge his physician on treatment choices that Cam felt were illogical. Cam tried to make sense of his treatment and the actions of physicians in numerous ways. He questioned patterns of miscommunication between his doctor and himself. He recalled multiple instances where he did not feel that he was able to adequately convey his experiences and questioned his ability to express himself in these appointments. He thus concluded that he may be at fault for not adequately expressing his experiences and concerns:

I went to the doctor, I don't know how well I expressed it. All its details seemed to be... gone... all that's in my memory now is, you know specific discussions dealing with living... I don't know how well I conveyed it to him.

Such hesitation or questioning of one's communication indeed formed the groundwork for narrative medicine, as effective patient-physician communication is considered central to both the medical and storied elements of effective clinical care (Charon, 2012).

6.7.1 Medicated Cam: The zombie effect. The identity of “Medicated Cam” came out of his descriptions in which the security provided by the medicalization of his illness may have

been more comforting than the challenge of trying to explain or manage his illness on his own. While the medical labels may have initially been comforting, Cam demonstrated the common struggle for ownership of his own illness as he described a feeling of loss of “Consistent Cam” to the medical system and medication (Frank, 1995, 2010). Cam described numerous questions and conversations that he wanted to have with his physician, but never had. Throughout his narrative, his reactions to medication in colloquial terms (e.g., the fog, feeling like a vegetable) were interwoven with more medical descriptors (e.g., increasing the dose, seizure activity):

I mean, I didn't want the seizures but I didn't want the fog. And if increasing the dose didn't help, maybe expressing it to me would- I wouldn't have had those moments where I thought: "C'mon Doctor, do something!" (Laugh.)... you know?

Cam repeatedly recalled conversations illustrating his attempts to make sense of his treatment and included hypothetical strategies to address his concerns regarding his lack of function and his difficulty with medications. Conrad (1985, 1992) noted this common pattern of questioning and re-evaluation of the role of Self in medical management of illness. Despite Cam's emphasis that he was not the medical expert, his descriptions made it clear that he had familiarized himself with medical terminology, medications, and research regarding medical procedures.

Throughout his narrative, Cam maintained a focus on the medicalization of his illness and repeatedly referred to the medications that his physician had prescribed him. Cam described his early experiences with anticonvulsant medication as feeling that he was in a “mental fog” but that he was able to maintain consistency and continue being functional at work. This was in contrast to the stronger reference that he used in regards to his second medication: “*adding lamotrigine made me a zombie,*” and repeatedly referred to feeling like a zombie trying to work in a human world. Again, I noted a turning point in which Cam had shifted from an individual who seemed

to perceive himself as able to function despite diagnosis and medication, to an individual whose medication significantly impacted his self-concept and separated him from the “human world” he used to be a part of (Charmaz, 1991). Cam’s increasingly powerful metaphors regarding his medicated state enabled me to gain insight into his experience of cognitive difficulties from an individual who experienced minor struggles (e.g., fog) in daily function, to a detached identity and exclusion of this identity from his everyday world (e.g., zombie), to extreme fears of being entirely unable to function (e.g., “becoming a vegetable”).

6.7.2 Medicated Cam: Fuelling the fire. When his Consistent Cam identity became inconsistent, Cam’s focus turned to the medications that he was prescribed as the external interruption to his identity. Despite the fact that he had experienced poor seizure control and an increase in seizure frequency, Cam attributed his change in function and subsequent change in identity to side effects of medication:

Cam: Ya, and that I’m attributing to, to the starting of the increase in medication because I didn’t have control of the seizures.

Me: Mm-hmm.

Cam: And I’m only basing that because basically nothing else changed in my life at that stage...

Me: So you feel it was really the medications/

Cam: /as the dosages increased/

Me: /associated with epilepsy?

Cam: Exactly and I would not, uh, say... up to that stage in 2004 when surgery was the option. But it would be 50/50 because... seizures, you know, who wants to have seizures? But for me, I also wanted to be back to that Cam that was productive and I thought, at

that stage, I was at a medication level that wasn't making me productive and the seizures, again, happened at the regular point cause they found the lesions there so... I don't think that, you know, unless they had me pretty much comatose on medication... I'd still have those seizures I think, no matter what level of medication.

Cam expressed frustration and a desire to be “back to the old Cam,” explaining that he had researched anticonvulsant medications in an attempt to make sense of why his physician insisted on using a medication that Cam felt was both ineffective in treating his seizures and problematic due to its cognitive side effects. Cam explained that his medication provided “fuel” that is “consumed by misfiring neuron,” leading to the formation of a “lesion around the misfired neuron” with each seizure, such that it would make the source of his Epilepsy visible “for possible surgery to find the focal point.” Therefore, his frustration regarding his doctor’s treatment and his medication, he retrospectively concluded that his doctor had an undisclosed purpose of “fuelling” the “misfiring neuron;” in a sense, “fuelling” the invisible source of Epilepsy in order to make it “visible” and ultimately, facilitating the removal of this seizure source. It appears that Cam’s trust in medical authority led him to make sense of his physician’s treatment, even if it involved deducing that his physician had a secret motive that he chose not to share with Cam over the course of at least a decade. His conceptualization of medications “fuelling” a neuron is likely a product of medical conversations regarding firing neurons, which is a dead metaphor commonly used in discussion of physiological processes, and may also have enabled him to accept his medications given their important role as “fuelling” and making visible the source of his seizures, even if this was discovered several years after living with these complications.

6.8 Back to the Old Cam: Removing Epilepsy

The identification of the possibility of surgical removal of the seizure source provides yet one more turning point, a point in Cam's illness career in which he shifted from someone with a chronic, incurable illness to someone with the possibility of a cure. Such a shift, involving the physical removal of illness itself, appeared to renew Cam's hope and shift from day-to-day living to hopes for the future (Charmaz, 1991). Cam's retrospective belief that his medications were responsible for any cognitive deficits was further illustrated when he described physicians finding a focal point for his seizures: a lesion that would always "hit him wrong" regardless of the level of medication that he was on. It appears that this lesion provided Cam with a culprit; an external source of his seizures to which he could attribute the disturbance to his "Consistent Cam" persona. Cam's discussion of this surgery is consistent with many published epilepsy narratives, in that the surgical removal of the focal point is seen as a victory (e.g., Kinsmen, 2007; McCallum, 2008; Seaborg, 2015). This is also consistent with many cancer narratives, in which individuals discuss the surgery as a prominent victory and as removal of the tumour being representative of the removal of the illness itself. In line with the rest of his narrative, he asserted that the removal of the lesion responsible for his seizures (i.e., the embodiment of his Epilepsy) would lead to the successful return of the original Cam:

Back to that consistent environment, right? Because that lesion is still going to hit me wrong... that lesion is still going to misfire, right? So I, I still at that stage wasn't necessarily concerned entirely about the seizures. It was... I wanted Cam back. You know? And I thought the surgery would do that.

Comparable to the majority of published epilepsy narratives involving surgical recovery, as well as cancer narratives involving successful recovery, Cam identified himself throughout the treatment process and named Epilepsy as separate. He personified the lesion identified as the

source of the seizures, explaining that it would “misbehave” and cause his seizures. He further interpreted its removal as the removal of both his seizures and his “Epilepsy” label. In recounting his experience with Epilepsy chronologically, Cam’s descriptions shifted after he recalled the possibility of surgery. This involved a shift from using biomedical terms for seizures and Epilepsy that had served as timemarkers in his narrative, to the identification and equivocation of the tumour itself as a culprit causing his seizure activity (Wilson et al., 2010).

6.8.1 Getting rid of seizures. It is interesting to note that the two elements that Cam previously used to define his Epilepsy remain after his surgery: his seizures and his medication. He appeared to justify these two elements as becoming less intrusive after the surgery, and in fact proceeded to decrease his use of medication against the advice of his doctor. Cam explained that surgery had eliminated the seizure type that was most problematic (i.e., complex partial seizures) but exchanged them for “violent nocturnal seizures,” whose descriptions closely resembled his traditional view of an epileptic seizure:

So... there was, it seemed obvious to me- and I would chew my tongue, the right side of my tongue. And that's where the blood, um, on the pillows would be, I'd slice my tongue. So, all I knew was that there was something obviously happening at night. Uh, it wasn't frequent, so it wasn't as though... uh, even a monthly thing. This was something that would happen even... maybe... three times a year.

The less frequent and less public occurrence of Cam’s seizures appeared to make him better able to accept these minor occurrences, despite their physical consequences of sore muscles and blood in the morning. Given the removal of his problematic seizures, of greater concern to Cam post-surgery was the desire to rid himself of the medications that he felt were no longer necessary.

6.8.2 Getting rid of medications. Cam described an attempt to communicate his

concerns regarding medication to his doctor but, when his doctor responded with a desire to increase his medications and control his seizures, he “took it on myself” to change his treatment without further consultation: “*stopping seizures is one thing but maintaining quality of life is... vitally important to me.*” Cam described his choice to decrease his medications without telling his doctor a “radical approach,” a “dramatic step,” yet detailed a “logical” and regimented approach to reducing his medications:

I can document each step of the process of weaning myself off. I'll wean myself off at this amount, I'll monitor my fogginess, I'll monitor my sleep patterns, I'll monitor, you know, any strange feelings...

Rather than success and relief, he described a mixed reaction when he successfully reduced the medication that he was on. Despite what he identified as a successful improvement in his daily function and quality of life, Cam framed the experience as an inappropriate act against his physician and reflects on the way in which he “offended” his doctor by not following his treatment plan: “*I went to him regarding what I had experienced which was now no longer seizures. And that I didn't feel medicated. Um... he took offense to that.*” This reflection is consistent with Cam's perceived role for medical authority, in which he has broken the code of conduct by not playing the role of the patient in the patient-physician hierarchy. This portrayal provides one more turning point for Cam, and reinforces Charon's (2006, 2012) stance regarding the importance of patient-physician dialogue in ensuring appropriate treatment and treatment adherence. One could say that Cam maintained medication as the culprit and emphasized that it was the medication, rather than the (now eliminated) Epilepsy or his physician. This enabled Cam to maintain the role of the well-behaved patient, as well as dismiss the possibility that Epilepsy may still be playing a role in his identity, as he placed his distrust on the medication with which he was being treated.

6.8.3 Getting rid of Epilepsy. While he never explicitly discussed distrust of his physician, his unvoiced concerns, choice to act against his physician's orders, and an eventual choice to seek a second opinion provides us with another perspective and another transition through which Cam's narrative has likely been re-scripted. This new neurologist reinforced if not introduced to Cam the idea that his past medication and stress regarding his medication-related limitations, more so than Epilepsy, were possible causes for his nocturnal seizures:

Me: So what would you call those seizures? If they're not epileptic seizures? What would you consider them?

Cam: Well, they're... ya, they're defined kind of differently... a lot of them refer to them as non-epileptic seizures. They're also called psychogenic... I would say, I would agree with [my neurologist] that my surgery was obviously a success because the complex partials were gone. And maybe the overwhelming sense of failure in every aspect of my life, you know, as far as... zombie outings produced, maybe produced the psychogenic non-epileptic seizures. I don't know about them being that violent, you know, where I actually split my tongue, to that level, you know. Would you do that in a non-epileptic seizure? I don't know but... lowering the dose seems to work for that.

Cam illustrated a different relationship and communication style with his second neurologist, including new terminology in reference to his illness. It could be that this change reflects his perspective from a later stage in time and in the course of his treatment. He emphasized more than once that he agreed with his perceived collaborative treatment decisions. Cam expressed trust in his new doctor explicitly because he is “*not going to be playing with my medication anymore.*” This element of “playing” with his medication again emphasized Cam's questioning of the treatment he was previously receiving, as well as the serious nature of medical

treatment. Again, he emphasized the medicalization and medications he was receiving as the problem that was limiting him, rather than the seizures themselves. He stated that he trusted his current neurologist based on the fact that the latter did not increase his medications and identified any ongoing seizures as “psychogenic non-epileptic”.

6.9 A Different Cam

Cam’s perspective of not letting Epilepsy rule his life indicated a positive attitude against an illness that was characterized by Cam as a significant adversary. Despite repeated concerns regarding his experience of seizures, Cam identified them as “incidental,” consistent with his attitude of attempting to dismiss his seizures as non-intrusive and instead identifying his medical treatment and anticonvulsant medications as the most disabling part of the illness. In reference to “who” Cam feels like these days and how others might perceive him, he identified feeling that he was “*back to the old Cam*” and, in regards to his peers: “*I think they see a different Cam now.*”

When asked about his current status in regards to epilepsy, Cam responded with the following:

Cam: *Um... I know I do to myself refer to epilepsy... and now, maybe a non-epileptic seizure... only as a reference point. Because I agree with [the neurologist] that prior to the surgery I had epilepsy. After the surgery, I don't think I do.*

Me: *Mm-hmm.*

Cam: *And so, only in that fashion would I refer to epilepsy as a condition that I had and now I have a possibility of seizures.*

The initial turning point that was Epilepsy in Cam’s trajectory was perhaps most clearly described by him in reflecting back after his successful surgery: Epilepsy became a “reference point.” He explained that prior to the surgery, he *had* Epilepsy but that the surgical removal of his

tumour also removed Epilepsy from his current identity. Cam was clear in aligning himself with his current epileptologist in that the seizures that still occurred were non-epileptic.

Cam frequently made contrasting statements regarding his relationship with epilepsy and his seizures, perhaps reflecting his ambivalence or unresolved feelings about it. When asked if there is a metaphor or perspective that he would take, he responded:

Cam: *I think that's why I use that phrase: "I wouldn't let epilepsy rule my, my life."*

Me: *Ya?*

Cam: *Ya. Then I can refer to the condition that produces the seizures. Cause the seizures themselves are incidental to me, personally. To others, I'll refer to it as seizures. For myself, it's a condition that results in seizures. And I won't let "it" rule. You know?*

Cam framed his narrative as beginning with a “naïve Cam,” whose lifecourse and timeline was shifted with time markers such as his first seizure and his diagnosis of Epilepsy. He identified “Epilepsy” as external to his Self, and his language characterized Epilepsy as an unwanted and overpowering travel companion that he conceptualized as “holding him back” and “ruling his life.” Such language is consistent with illness narratives that portray the illness as an external entity that must be fought (Kirmayer, 2000; Plug et al., 2011). Cam identified the most tension between his concepts of Self and Epilepsy as caused by a lack of understanding of his symptoms on the part of himself, others, and even his doctors. Kiliñç and Campbell (2009) suggest that greater understanding of epilepsy facilitates integration of Epilepsy into one’s social identity, a process in which individuals arrive at a more positive sense of self. Cam’s process of increased understanding and acceptance, however, appeared to lead him to a more pessimistic perspective, illustrated by a cautionary statement about the disappointment associated with attempting to remain optimistic when one may ultimately be defeated by Epilepsy. Many individuals appear hesitant to discuss their illness until they have overcome it, regardless of how

this might be defined. Cam appeared to have overcome his illness through a successful surgery that removed the tumour—a source of his seizures and the “Epilepsy” label.

6.10 Conclusion: Living In the Now

Cam communicated significant changes in his life through both formal medical labels and colloquial descriptors of Cam at each new phase. His capitalization of Epilepsy provided a separate identity for the illness, while his emphasis on his own consistent function despite illness created an anti-Epilepsy identity full of metaphor. Using Frank’s typology, Cam’s can be seen as a restitution narrative in which he has experienced his diagnosis and changes in his health surrounding Epilepsy as chaos, but is able to speak to us retrospectively and present his post-surgical (and “post-Epilepsy”) experience as one that he has overcome illness due to the physical and symbolic removal of his Epilepsy identity (Frank, 1995, 2010). Nearing the end of our conversation, I asked Cam to elaborate on the synopsis that he had provided in his written narrative:

Me: Um... well, I want to ask you, ask you about your final synopsis. Because you said that: “My final synopsis would be that less optimism equals less frustration.”

Cam: Mm-hmm. It should say... realism is what, is what has to be- and a lot of this came from meditation and from the coffee club discussions- because a lot of them who have had it for, especially the ones who have had it for most of their lives, it’s a point of... you know, this is where it is. You can’t dwell in the past. You can’t (laugh), you know, you can’t put, well “Hope for the stars.” You have to live in the now, you know.

Cam’s portrayal of himself in the third person would be consistent with Frank’s (1995) detached individual who was unable to report on the illness experience as it occurred, but rather reports the events in retrospect. Particularly consistent with cancer narratives is Cam’s restitution

narrative once a source of his illness, a tumour, is identified and removed (Frank, 1995). Cam's narrative followed in much the same vein as many recently published epilepsy autobiographies (e.g., Powell, 2014; Seaborg, 2015; Simkin, 2010). These autobiographies are restitution narratives; they are authored by individuals who have experienced the chaos and confusion of epilepsy introduced as a chronic illness, followed by unanticipated but successful surgery (Frank, 1995; Wilson et al., 2010). These narratives are written in looking retrospectively at the chaos from the safe, healthier position of one who is no longer (or minimally) afflicted by the illness.

Along with numerous recent published narratives of those who have undergone epilepsy surgery, Cam's narrative introduces new stories regarding experiences with epilepsy and requires reconsideration of the stages of integration of the illness identity (Frank, 1995, 2010; Kiliç & Campbell, 2009). Many sources (Kiliç & Campbell, 2009; Mathieson & Stam, 1995; Rätty et al., 2009; Whittemore & Dixon, 2008) make reference to acceptance and integration of the illness identity to lead to a more holistic sense of self, whereas Cam would be considered as having a less healthy approach given his consistent maintenance of a compartmentalized identity in which he distinguishes himself (frequently referred to in the third person, as "Cam") from his illness (Epilepsy), his symptoms (seizure types), and treatment (medications and surgery). While this approach may be detrimental in individuals for whom the illness is chronic (i.e., never resolved), it may be that it is an adaptive approach for individuals like Cam if surgery does in fact resolve their epilepsy (Kiliç & Campbell, 2009). It would appear that he has achieved a level of "acceptance" by focusing on the present in which his illness, embodied as a lesion, was removed through surgery.

While Cam was an individual for whom surgery and conceptual removal of the epilepsy label was possible, Rose is an individual for whom epilepsy surgery was considered and found to be not suitable. She presents us with the narrative of an individual who, much like Cam, is

undergoing a process of constant changes in identity. While Rose also focuses on time, her shifts in time are portrayed as degeneration with epilepsy and age, rather than rejuvenation due to the removal of epilepsy. Furthermore, her portrayals are framed by the social boundaries that she uses to define her degenerating health, whereas Cam's portrayals are framed more so by his relationship with his body and its experience of time. Let us now turn to Rose and consider her experience of epilepsy.

CHAPTER SEVEN

Rose: Boundaries of a Safe Space

7.1 Meet Rose

I met Rose through a colleague who had informed her of my study. She was a divorced woman in her late 50s who lived on her own and had a small but supportive network of neighbours and friends. Our first meeting was over lemonade in her backyard, as she was minimally comfortable travelling too far from home given the frequency and severity of her seizures. In this encounter, I explained that I was looking to hear about her experiences with epilepsy in whatever way she might choose to communicate them. She quickly made it clear that she had a lot to communicate about epilepsy, and she expressed a great deal of frustration with the increasing role that seizures and medications had come to play in her life. I provided Rose with the written description of my study and we left it that she could take her time to write down her thoughts, after which we would arrange another meeting.

Two weeks after our meeting, I received an email from Rose with an attachment entitled “Devon’s file.” What followed our previous relaxed conversation was a written narrative that held a different tone, as indicated by her opening lines:

Strange. I have a few things I do to make myself comfortable when I have to do something I'm not comfortable with. I am not comfortable doing this. (Written narrative)

This was Rose’s introduction to a tension-filled narrative that alternated between lists, questions to herself and the reader, short passages relating to the linear chronology of her epilepsy experiences, and reflections on social interactions as they related to her epilepsy. Rose and I conversed over email both before and after she sent me her written narrative, in which she expressed discomfort with the writing process and we discussed her tendency to avoid

conversations surrounding epilepsy. She identified herself as nervous but was nonetheless open to having a conversation about her writing and her epilepsy experience. I interviewed Rose in her home and we talked over tea, providing an opportunity to converse in a space in which she felt comfortable. We took breaks to freshen our cups of tea, pet her cat, and look at a stack of epilepsy education materials (e.g., community newsletters, magazine articles on epilepsy) that Rose had gathered to show me. It was quite evident that epilepsy was central in most of her activities, as even our “break time” turned to conversations about neighbours’ check-in visits or her list of errands for the day, which included contacting her neurologist and picking up medication.

Rose’s expressive tone made her an animated and interesting storyteller. It was apparent that she used humour to discount painful aspects of her past or current reality, as several topics were addressed with sarcasm or dismissed with nervous laughter. Rose occasionally had difficulty remembering words or events, and we returned to certain topics later to attempt to address forgotten items. At other times she quickly shifted from one event or time period to another, creating a disorganized plotline. In reviewing Rose’s narratives, it was at times a challenge to find order in the disorder. Rose’s demeanour changed throughout our conversations. At times she fit her descriptions of her “younger self,” a woman who was assertive and strong in daily life and in dealing with epilepsy. At other times, she appeared defeated and frustrated by her physical and psychosocial realities.

Rose explained that, at age 21, she had begun experiencing “grand mal” seizures without any warning; that is, she had no conscious anticipatory feelings or physical indications that these seizures were about to occur. She described about 15 years during which her seizures were well-managed with medication, but explained that she frequently had to try different medications to minimize the number of seizures she experienced. Rose stated that her seizures had become more

frequent and more severe in the past 10 years, leading her to have to leave her job and go on long-term disability. She expressed significant frustration with her increasing struggles to manage her seizures explaining that she felt that the medical community had little left to offer her as she aged, as the nature of her seizures changed, and as they had fewer treatment options to offer.

7.2 Epilepsy As a Struggle for Social Control Over Time

After reflecting on the primary metaphors and overarching themes of Rose's narrative, it became clear that social control and time were central to her epilepsy experience. This was based on both explicit and subtler statements in our interactions. Her need for control surfaced most frequently in metaphors and narrative sections referring to her social world. We first encounter Rose's awareness and need for social control after her first seizure, then follow a continued struggle for social control with a focus on interactions with family, peers, and the medical system. She reflects on time, turning to the impact that aging has had on her increasing battle to control both her epilepsy and her social world. Over the course of her narrative she shifts from a woman claiming to have complete control, without any impact of epilepsy on her social identity, to a woman who anticipates being entirely defined by her illness.

Throughout her narrative, Rose attempts to define the boundaries of her social world in which she can safely reside. This appears to be a reaction to the perceived boundaries imposed on her by her epilepsy, including its influence on her physical and psychosocial realities. Despite the fact that she has been living with epilepsy for 30 years, Rose perceives an inability to establish a secure space given the constant changes associated with her illness. She perceives an increased loss of control as she ages, and with this loss of control the boundaries of her social world shift and shrink. As such, we hear a chaos narrative in which uncertainty is the norm. Rose recalls experiences scattered across different times in her life causing lines to be drawn and re-drawn,

named and re-named (Frank, 1995). The urgency in Rose's attempt to stake out her safe territory is palpable, in a battle against time in which control continues to slip further out of reach.

I observed several rich metaphors in her narrative that introduced the impact of epilepsy on Rose's social world in particular. While she never refers to it as such, epilepsy often appears to serve as the shifting boundary between her own and others' realities. In the social realm, Rose's first seizures involve classmates, nurses, and family members who indicate that her illness experiences will be left for her to face on her own. She attempts to identify and control the boundaries that keep epilepsy out of her life, but later finds herself limited to the safe space of her own "nest," which continues to shrink over time. These social boundaries include those individuals that she considers safe to let in as opposed to those that may be a threat. In the medical realm, Rose appears to use the mechanical "fix it" attitude to advocate for herself with physicians, seeking help for a body that needs "fixing." She reflects on the progression of her illness and evaluates how she has to adapt her strategies to maintain control. In this way, her narrative provides us with an opportunity to reflect on the role that aging plays in an individual's evolving perspectives on the fragility of her social and physical selves.

7.3 Rose's Seizure Narrative: The Face in the Mirror

Rose did not write about her seizures, apart from identifying the labels she gives them. Like approximately 21% of individuals with epilepsy, she experiences primary tonic clonic seizures without warning, is unconscious for the entire event, and is aware only of the events following her seizure (Berg et al., 2010). Her seizures have been very visible to others despite their lack of visibility in her own life, or alternatively her lack of conscious presence. As a result, her narrative is not of the seizure itself but of the events following her first seizure. Because she

did not address her seizures in her writing, apart from providing a few one-word labels, I asked her about her first seizure in an attempt to get a sense of how she perceived it.

Rose's first seizure experience seems to both impact and mirror her overall epilepsy narrative structure. First, her primary focus after her seizure is the reaction of others. Second, Rose experiences difficulty in capturing the post-seizure physical symptoms, eventually dismissing a headache and "fluffiness" that leaves her detached from her social circumstances. Her passage struck me in that, even at the medical level, she was forced to look in the mirror — to face herself and her condition alone — rather than have someone speak to her or ask her how she felt. This mirror-episode, quoted below, provides a powerful introduction to the 30 years that she has been living with epilepsy, in which she experiences ongoing feelings of isolation as she struggles to make sense of an uncontrollable existence. She recounted her experience in a monotone voice, with occasional pauses and self-corrections when she appeared to become uncomfortable. While Rose frequently used a sarcastic tone, in this excerpt as well as throughout our conversations together, I often had the feeling that this sarcasm might be a defensive strategy, an emotional boundary, that she used to protect herself from the pain that lay beneath:

I was in school in the middle of exams. (Laughter). Uhh... I didn't even know I'd had one, I just knew I woke up feeling like hell and I just... sort of brushed my teeth and ran out.

Cause I knew I was late and I was an hour from school. Hopped on a bus and people were staring at me and stuff. I had no idea what was going on, I was, my head was, well... post-seizure, serious headache and fluffiness... well, fluffiness is a nice way to describe it but...

I went to the exam and the teacher said, "I think maybe you should go see the nurse." And I said, "I think I'm okay." "Do you want to write the...?" And eventually I started trying to write this exam and I said, "I think you're right, I think I need to go see the nurse." So I went and saw the nurse and, she asked me if I knew what I looked like and I, I had not

seen myself, I looked in the mirror and I was covered in blood. My lip was cut. I had fallen in the bathroom. Had a seizure in the bathroom. Marble sink, that kind of deal, old house, and uh... Two weeks later I did it again and they put me in Montreal General for a couple weeks and, a diagnosis and, so... yep.

The description of this first seizure sounds much as though an observer is narrating it. Rose emphasizes the observations and interactions of those around her, highlighting her sense of detachment from the experience as well as her primary focus during post-seizure recovery. She recalls strangers in the public arena staring at her, though she is unable to make sense of why. She recalls an authority figure, her teacher, attempting to dictate her actions while she attempts to prove that she can still function appropriately and write an exam. Finally, she recalls an individual in the medical arena, the nurse, forcing her to acknowledge herself in the mirror and make sense of her own condition. Despite what sounds like a shocking physical appearance, Rose identifies three social interactions in which individuals chose not to offer support or speak to her regarding her physical state, but instead passively forced her to manage it independently.

Rose has likely recalled and described this first seizure at numerous times. As such, it may be an edited account of Rose's experience but it nonetheless reflects interesting trends in her perception of social realities at the time of her first seizures. In each interaction, Rose recalls others staring or treating her differently due to her appearance, or possibly her condition. It may be that her interpretation of these early events colours what could be relatively neutral experiences, such that she perceives others as having mistreated her (i.e., felt stigma) when in fact no "enacted stigma" took place (Denzin & Lincoln, 2000; Scambler & Hopkins, 1990). While no one may have directly mistreated Rose during this first experience, she nonetheless internalized these experiences (i.e., staring or confusion on the part of strangers, a lack of open discussion on

the part of doctors) and has decided that she must create a safe identity for herself in which others will not have such reactions (Faircloth, 1998; Radley, 1993).

From the physical perspective, Rose identifies her seizure based on the post-seizure experiences, the physical and cognitive experience of a “serious headache and fluffiness” that she, retrospectively, has come to associate with her post-seizure mental state. It is possible that, had she not had physical evidence (i.e., blood) or other individuals telling her that something was wrong, Rose may not have identified these symptoms or recalled this particular morning as out of the ordinary. Thus, she is largely reliant upon others to help her make sense of what indicators are relevant in regards to a seizure (Charon, 2006). Rose’s closing statement provides a take-home that she may have learned during these early interactions. She describes her second seizure, stating “*I did it again,*” suggesting that she accepts culpability despite her own lack of control over this occurrence. Her description implies being penalized for her “deviant social behaviour” (Parsons, 1951; Schneider & Conrad, 1983), the punishment being both imprisonment when “they put me in” the hospital, as well as a medical diagnosis, or label, of epilepsy.

Starting with her first seizure, Rose describes what appears to have become an ongoing battle for control over boundaries. Her battle is often against an undefined “other” including family, physicians, the public, and even herself. The boundaries most often delineate the safe and unsafe spaces in her life both during and after a seizure. In these unsafe spaces, her illness and others appear to take control of life decisions (i.e., work, hobbies, social opportunities). Her use of metaphor in trying to build a “nest” that keeps getting “shaken” over time may illustrate a perception of an increasingly fragile and unsafe world in which the boundaries of her safe space continue to shrink (Schwabe et al., 2007). These boundaries are often imposed or suggested by others, but she identifies herself as being in control of these decisions. Her proactive role in her

own medical care, as well as her choice to manage her own identity in the context of epilepsy, may provide her with the security that she has control (Faircloth, 1998).

7.4 Social Control: “You Lose Control of... Who You Are”

Rose presents us with a powerful look into one individual’s struggle for control. This struggle includes a perceived fight against the physical and psychosocial limitations that epilepsy imposes, as she attempts to protect her identity. She conveyed these struggles for control through clear statements as well as minor nuances. For example, she identifies epilepsy as the “*ultimate loss of control*” in a tone that shifted from cautious, to raw, to sarcastic and dismissive in the span of a few sentences:

Well... it’s one thing with epilepsy, I dunno, it’s uh... the ultimate loss of control. Cause it’s there for however long, whether it’s two days or two weeks or, or you know five minutes... you know, you have no control over yourself, you don’t remember, so you not only lose control for the few seconds of the seizures but you lose control of... who you are, what you are, anything... for whatever recovery period of time. So, you have to just accept that in some way. So I just accepted it by deciding that it wasn’t going to be part of my life when I first got diagnosed. You know- ya, whatever. Um... ya, whatever I’m getting on with what I do!

Rose describes her initial diagnosis as a time in which she denied the illness and its ability to impact her life. She equates epilepsy with the entire time period during which she experiences a seizure or cluster of seizures, as well as the time she is recovering. As such, the first boundary of safe space that Rose draws is one in which her “non-epilepsy self” is in control. She initially defines her unsafe space as existing only when she is physically experiencing her epilepsy. While Rose describes an initial response to her diagnosis of deciding that “*it wasn’t going to be part of*

my life,” she learns over time that despite her attempts to ignore this unsafe space or “epilepsy self,” epilepsy will play a role. She then attempts to regain control by defining the aspects of her life in which her “epilepsy self” will exist. These boundaries shift with time as Rose is forced to re-adjust to the growing role that epilepsy plays in her daily life.

7.4.1 Family secrets. Rose’s description of her first seizure identified several individuals (i.e., peers, teacher, nurse) who gave her the impression, if only passively, that her seizures were not something to be addressed in a public forum. Rose repeatedly talked about her mother’s level of secrecy surrounding epilepsy. She explained that her maternal aunt’s history of epilepsy was a “family secret” that her mother never shared with Rose or any physicians, even when she was directly asked about a family history of epilepsy. Rose described her mother as unable to discuss or support her, even when Rose explicitly asked her to attend appointments and to educate herself regarding the needs of an individual with epilepsy. Based on her mother’s actions, Rose likely inferred that she must not speak of her epilepsy around family, creating the first of several boundaries that Rose negotiates to claim control over: *“I, I even sat in the doctor’s office with my mom and tried to explain to the doctor that she needed to understand how to take care of me after a seizure.”*

The parental choice to model a level of secrecy surrounding epilepsy has been referred to as “stigma coaching,” often leading children with epilepsy to perceive that their illness is something that they should feel ashamed of or that they should keep hidden from the public (Schneider & Conrad, 1983; West, 1985; Ronen et al., 2001). I suspected that Rose’s reflection on her mother’s reluctance to talk about epilepsy, as modeled by her mother’s own parents and by her mother’s continued action, likely has led Rose to carry the burden of her own illness identity as a “family secret.” This often creates a perceived stigma, particularly when a parent models that a child should be ashamed or secretive regarding her epilepsy (Scambler, 1986; Schneider &

Conrad, 1983). While Rose at times discussed her desire for an aware and supportive family, she specifically relays that it is her family's tradition to maintain separate realities, and thus she makes it her responsibility to ensure that her family not witness her seizures. She repeatedly identified her epilepsy as a separate "it" rather than part of her self, making the illness an almost tangible barrier between her and her family members. Rose uses this separation as an early introduction and rationale to why she prefers to joke about her epilepsy when she must talk about her illness-related experiences, both with her family and with others:

Rose: I've asked family to look at some of the readings that I've sent or... um... Time magazine had an article there and I thought, "You know, just go out and get the magazine" and none of my family did. They just didn't, they don't want to think of it as something that exists in their... it just isn't really real to them. So... so it's easier just to... if I want to bring it up, I bring it up in a joking kind of way.

Me: That's the easier way to talk about it? So if it doesn't exist for them... how does it exist for you? How do you kind of... reconcile that?

Rose: Ah... it's like I live out here and they live back there, back east, and they never come out here. So it's the same sort of thing. I have a different reality and... the experience in my family has been anybody who's moved away are responsible for going back to visit. You know, so. Your own reality is your own reality but... the family is... you know, you go there to partake.

Me: And if you go there and... have a seizure? Or if you go there with epilepsy?

Rose: I always have a seizure when I come home. (Laughter.) So that's like after stress kind of thing. That's when I usually have seizures.

Me: So have you ever had one with them?

Rose: No. Not around the family, no.

Rose described the divide between her and her family as both physical and symbolic. This divide is one in which she and her family not only have different home provinces but also different realities. Rose feels that it is her duty to repress her own reality when she visits the family and instead participate in their reality. She perceives it as her responsibility to create boundaries between her controlled (i.e., seizure-free) and uncontrolled moments, so that she can be with her family in an epilepsy-free space. While her family members have never witnessed her seizures, it is a common occurrence for her to have seizures after returning from a family visit. Again, we hear Rose taking control of her seizure experience, implying that she is able to present her family with an epilepsy- and seizure-free Rose.

Rose's experience is a noteworthy contrast to the other participants' parental reactions. While Rose describes a mother in particular, as well as a family, that denies the presence of her illness, the other participants describe families that were supportive. Grace and Hannah had mothers who they described as protective and inclined to treat them as "victims" of the illness, similar to Ronen (2001) and West's (1985) description of parents who take an "avowal of normality" but become protective by acknowledging the child's epilepsy and avoiding activities that might aggravate symptoms or cause danger. Both women appeared to react by actively working against this victim role and, in adulthood, had come to a point where they were comfortable discussing their epilepsy—including with their parents. Cam and Clark spoke less regarding their parents' initial reactions but did identify a high level of support. They both identified open relationships with their parents and siblings, with parents who were willing to discuss epilepsy. While this could align with Ronen's (2001) parental model of accepting the illness and speaking about it when necessary, it more likely reflects the adjustment made in adulthood as Cam and Clark took a more proactive role in discussing their epilepsy and modeling

their comfortable level of discussion. This is yet one more moment in which this small group of participants is able to capture a diverse range of experiences.

7.4.2 Social rules: “Make light and move on.” Not only does Rose feel the need to exist in a different reality when with her family, this also colours her perception of those who witness her seizures. She sees it as her responsibility not only to control her seizures, but also to support those who do have to witness them. Here, she relies on her and her family’s solution to her seizures: they are not expected to understand her experiences and instead choose to “make light of it and move on.” Throughout our interactions, as well as within her narrative, it was clear that she relies on humour to escape the pain and the fear that she experiences. It appears that this strategy, seemingly learned from family interactions, is but one approach that she takes in establishing a safe space around her illness:

So curious... but umm... but I need their support as much as umm... for those people, including my family, who have never seen a seizure or have never been around me when I’m having a seizure, umm... they can only make light of it cause they don’t understand.

From a narrative stance, Rose repeatedly deflects the focus from herself to a focus on the “other,” or another individual’s perspective. She repeatedly states that her behaviour and her necessary boundaries are not for her own sake. It is almost as though she is standing next to the witness in these moments, observing her seizure. Her perspective could be seen as providing empathy for the observer, though it also provides her with distance from her own experience. She encourages us to focus instead on those witnessing her seizures, even when the questions are directed at her. The following statement reflects that this diversion and distancing from the seizure experience is something she does with minimal awareness:

Rose: It’s a medical condition, get over it, you know?

Me: *Mm-hmm.*

Rose: *Although, it's... got a lot attached to it... in physical health, sometimes. And... I'm sure there's a lot emotionally that goes on for those caregivers but... I haven't been on that side (Laughter), so I don't know. You know, it's gotta be, you know, "Oh there she goes again," you know? (Laughter). Um, there's gotta be some difficulty there.*

Me: *How about on this side?*

Rose: *What?*

Me: *There's a lot that goes on "on that side"...*

Rose: *Oh, on this side! Um, oh... (long pause)... it sucks.*

While our conversation started with Rose's experience of a seizure, she shifted to describe the caregiver's emotional experience of a seizure. Her pauses in speech as she moved through this description, along with the nervous laughter that punctuated these descriptions, emphasize her discomfort and her desire to move attention away from her own seizure. She explains that those who experience a seizure with her "*get the hard end of the stick,*" again diverting attention away from herself and her needs. Rose emphasizes that conversations about her epilepsy are difficult and she explains that, during these conversations, she is usually "*busy making other people comfortable... to be around it.*" She explains that the way in which she does so is by, again, reverting to the humour that she learned with her family. In this passage we hear self-deprecating humour in her statement "*There she goes again!*" Here, she also acknowledges that talking about epilepsy is difficult for her and indicates her own need to "*make light and move on.*" Throughout her narrative, Rose appears to distance herself from her own experience and attend instead to the discomfort of the "other." This highlights a coping strategy in which she appears to focus on making others more comfortable rather than focus on her own seizure experience and possible discomfort (Monzoni & Reuber, 2009; Plug, Sharrack, & Reuber, 2009).

7.5 Social Control: Defining Seizures

The majority of Rose's seizure terminology and descriptions make reference to her post-seizure recovery, including both the physical and psychological indicators that she relies upon to indicate that she has had a seizure:

Names I use for epilepsy and seizures:

- *Epilepsy (not epileptic)*
- *I think I had a seizure (after - because I'm never really sure of anything after a seizure.)*
- *I fell over. (Did I fall over?)*
- *I seized.*
- *I flopped. (Written narrative)*

She explained that she always uses these terms tentatively and in the past tense, given that she is only aware of the seizure after its occurrence. She further explained that she must rely on others to fill in the details of the seizure occurrence for which she is not consciously present. Rose emphasizes that her post-seizure experiences, along with the medication side effects, are more problematic than the seizures themselves:

Well, there's a cloudiness and just a, an... just an inability to- to work. Walking into things. Not being able to speak. Ah, not remembering words. Let alone, not being able to speak. Not being able to come up with the words you're trying to get out, but not being able to say it even once you've got it. Umm. You know something's wrong! You know the people around you know something's wrong. Umm... ya, after a seizure you've got a pretty good idea something's wrong. I do... anyway.

She repeatedly refers to the "cloudiness" she experiences after a seizure. Further, she describes the many ways in which she experiences "an inability to work" in reference to not only her occupation but to herself as a physical being, listing many physical, cognitive, and social

functional difficulties. This reference to “not working” reflects the mechanical understanding that patients and physicians have used to make sense of their illness-related limitations, in regards to a physical system that is not working (Lakoff & Johnson, 1980; Zaner, 1988, 2004).

She appears to rely mainly on her comedic and mechanical references (e.g., flopped, seized, fell) describing her seizures from an objective perspective, with subjective reports of her own experiences of “cloudiness” and uncertainty. Rose’s emphasis on “*people around you know something’s wrong*” prior to acknowledging her own awareness indicates an accurate temporal sequence of events but also emphasizes the sequence in which Rose prioritizes the impact of her seizures. Monzoni and Reuber (2010) suggest that, from an interactional perspective, the provision of both objective and subjective seizure reports enable the individual to appear more in control, though they may nonetheless be having difficulty coping with the experience. Rose’s comedic and mechanical references provide further support for her attempt to distance herself from the often scarier terms of “seizure” or “epilepsy” (Plug, Sharrack, & Reuber, 2010). When she does turn to the term “seizure,” Rose does so in a hesitant and tentative way. In elaborating on her tendency to use past tense in reference to her seizures, Rose spoke of many instances that increased her fear surrounding seizures. She provided a potent and fearful example of possible events that could occur while a person is recovering from a seizure, in moments of uncertainty when one is not consciously present and in control of her self:

Well, like... what’s... I’m pretty sure it’s never happened to me, not that I would know but I read about a lot of women with epilepsy who have had trouble with sexual abuse. After seizures. Because they, they’re not there.

Rose used this example to illustrate how she would feel safer if she had trusted others around during or after a seizure. She explains that this would ensure that others could be present when she herself is not consciously present. In this powerful statement, she captures the

vulnerability of the individual who is consciously “not there” and thus unable to control her or his actions, as well as the actions of others towards them. She extends her example to include all women with epilepsy, and only tentatively reassures herself and the listener that she is not in danger of this threat.

Rose explained that, when she began having seizures in her 20s, she would often relate her post-seizure experience to a hangover, given the similarities in physical experience, whether it had been a night of drinking or a seizure. A hangover would have been a way to normalize this event and express it to her peers. It would also enable her to describe a seizure in a way in which she could describe an accessible and embodied experience to physicians (Kirmayer, 2000). I wondered in retrospect whether Rose’s use of a hangover was purely a reference to her physical state or whether there was also a similarity to the negative result of drinking too much alcohol, indicating a punitive consequence for deviant behaviour. Rose acknowledges that she continued to consume alcohol even when she was not supposed to, and I could not help but wonder if her embodied experience in the post-seizure state was not accompanied by the same culpability that she experienced after a night of drinking.

Rose’s post-seizure description has changed over time. She describes her recovery as the “aftershock” similar to a “really bad hangover,” though she quickly emphasizes the change that has occurred in this experience. She repeatedly turns to the deterioration of her condition and to the uncertainty that her seizures present:

Me: So aftershock is after a seizure?

Rose: Ya. It’s ah... I used to feel like I was, you know, like had a really bad hangover like a serious hangover but it’s ah... gotten a lot worse. I can be out of it for days, or weeks, or... sometimes a month, just really not feeling good. Just cloudy, or unsure of... myself or whether I’m going to eat properly or... take my drugs properly or... (trails off).

Time plays an important role in this description, as Rose describes her post-seizure recovery as having worsened with age. She makes the distinction that the period after a seizure has become worse in that she can be “out of it” or “unsure of myself” for days. Her description of uncertainty towards herself is a significant shift in her perception. She could previously attribute many of her daily problems to epilepsy (including seizures and anti-epileptic medication) as an external cause. She now identifies herself as possibly playing a causal role in daily problems such as whether she eats and takes her medication. Due to her inability to trust and care for herself, she describes her further precautions now that she has aged and has lost her ability to monitor her own recovery and well being, including relying on timers and other individuals.

With age, Rose describes increased uncertainty towards herself and increased reliance on others. As an independent woman, she expresses fear and frustration at this need to rely on others, and questions whether her illness may take over her identity entirely when she is unable to function. She explains that a diagnosis of epilepsy already implies mystery given the uncertainty of the illness itself, but that with aging she experiences medical and physical uncertainties for which no one has prepared her. Rose appears to be questioning who she can trust even more than before, and she becomes fearful at discoveries of hormone-related changes, as well as sudden death. These include a lack of information regarding aging and epilepsy, including the impact of menopause and hormonal changes. Rose explains that no physician has ever told her about the possibility of SUDEP (i.e., sudden, unexplained death in someone with epilepsy who was otherwise healthy; Nashef, So, Ryylin, & Tomson, 2012), indicating both fear and a greater awareness of mortality. She further expresses her loss of self-control in describing new experiences of incontinence and vomiting during seizures, again reflecting a sense of decreased agency, increased mortality, and increased need to rely on others.

Rose describes the increased severity of her condition over time as also including “multiples,” in reference to multiple tonic clonic seizures in close chronological proximity. She again relies on slang to distance herself from the fearful reality (Monzoni & Reuber, 2009). She explains that she used to manage herself more easily because she would predictably have one seizure usually in the morning, but that she now experiences multiple seizures in a row, leaving her little time to recover or gain clarity on her circumstance before the next seizure occurs. Rose provides a description of the danger of having seizures in the bathroom, particularly when one lives independently. It is evident that mortality is a frequent thought, as she reflects on aspects of the seizures that are life-threatening. In the context of having “multiples” in the bathroom, Rose elaborates in great detail and reflects on a neighbour who passed away in her bathroom and was not found for three days. Not only is Rose’s narrative structured by her reflection on her own aging process, but the stories that she chooses to share reflect her frequent thoughts on others and the aging community around her:

Um, course the old lady who lived next door, she died... she died in the bathroom. She was there for 3 days after she died. I noticed the light was on. So it's a... I mean, it's a humane thing but I'm letting them know that I'm having more of a likelihood of this happening. You know, I'm not going to fall on the floor and be dead in 3 days. But that felt a little strange... I think I know my neighbourhood pretty well. The people behind me, I feel comfortable with both sides. They both know that I fall over on occasion and I, I don't think, you know- they're concerned if they don't see me for a couple days, which I appreciate.

Given Rose’s fear of her loss of control and mortality, she struggles to maintain social control while identifying trustworthy sources of support. This is another process that progresses over time, and in which she experiences both positive and negative social encounters that shape

her perception of the boundaries needed to enable her to maintain some sense of control. Lakoff and Johnson (1980) identify humans as physical beings who experience the rest of the world as outside of us, and as such we impose boundaries in order to negotiate the territories in which we exist. When Rose's physical self and her medical condition fail her, she indicates a turn to neighbours, allowing them to cross the boundary that was once a private and independent world. This reflects her prioritizing of survival and an attempt to regain control over her illness.

7.6 Social Boundaries

In an attempt to establish the control she desires over her own life and decisions, Rose repeatedly identifies the way she has resisted the control, the boundaries, that others have indirectly tried to impose on her. Initially, she experiences and reacts to the familial and broader social boundaries, with the reactive and territorial boundary of a guarded and self-deprecatingly comedic personality (Lakoff & Johnson, 1980). When physicians attempt to limit her activities in order to protect her from epilepsy-related injuries, she again pushes back and believes she is being penalized. She acknowledges that these changes may be necessary but insists that these decisions are her own, and the importance of being empowered to make these decisions for her self. She describes her first reaction to her epilepsy and the way in which she maintained an identity in which epilepsy was not "*part of my life:*"

Um, I meant like... I ignored it. I was on a career path... um, and I didn't want it to be part of my life. Any part of my life. I would take my meds but I would pretty much ignore it. It's not that I went out- I pretty much stopped drinking as well, not totally then, but I don't drink anymore. It's bloody expensive. That's one reason. But with the meds and stuff, there's no way, with the meds I'm on now.

Based on Charmaz's (1997) reactions to illness, Rose appears to experience her diagnosis as a brief interruption on her pre-determined career path. Nonetheless, she quickly clarifies that she did make minor adaptations, including taking medication and, eventually, a decrease in her alcohol consumption. She therefore acknowledges epilepsy as an intrusion in acknowledging and adapting to some epilepsy-related limitations. In regards to her illness identity outside of social relationships, this is the first adjustment made to limitations in her independence. She describes this as a progression, from minor accommodations in her actions to increasing restrictions on her behaviour. Time plays a central role in the boundaries imposed to keep her safe, as well as her perception of control over these boundaries. She recalls nearly getting into a car accident during a seizure, after which she identifies the personal choice not to drive:

But I decided then, no more driving, shortly after that. Just... but again, it was for some other people, not for my sake. I didn't want to be responsible for hurting other people and I... finally came to the realization that I quite, quite easily could be. I didn't hand it [driver's license] over, I just never went back to it, to driving again... I was able to have control. So that helped.

Rose emphasizes the need for control over this decision, as well as those that follow. The phrasing of each decision is similar each time. These are limitations dictated by her illness and her physician, but that she identifies as decisions that she makes in her own time and are her responsibility. Included in this list are decisions such as drinking, driving, working with power tools, and climbing ladders. In the instance where she chooses to no longer use power tools, she explains that her father has to “*meet me on a different level*” and that he may perceive her as a coward, given that she is no longer able to engage with him the way that they used to, by working with tools. This description reflects Rose's perceived devaluation, in that she is no longer

meeting her expected role as a daughter and may be held responsible for the limitations imposed by her illness.

Perhaps the most difficult decision that Rose takes responsibility for, despite it being imposed by her illness, is the choice to leave her job. With a role in the medical field, Rose's job was to fit, design and build braces for patients with physical limitations. She again describes a decision made for the sake of others, in which she must sacrifice her own self worth for fear of doing greater harm to others:

But I couldn't, that was, what I couldn't do as a job was I couldn't relate properly to patients, it was not fair to the patients... I had to ask my neurologist for a- well, he kept asking me to think about not working with power tools anymore and that was a big thing then, cause I've always worked with my hands and with power tools... grinders and saws and... all those dangerous things for epilepsy, and um, I sat with this letter on my fridge for about a month before I was willing to hand it in to work that said I should not be working with power tools and this was a dangerous thing so it completely changed- well, for one thing it would mean that I would never get a job outside of the place that I was working because nobody would hire me cause I couldn't do half the job.

Despite an initial intention to move on with her career path, Rose very reluctantly chose to leave her job. The insurance company is identified as possessing, and reminding her *"they have full control over my life."* She repeats her feeling of loss of identity when she is no longer able to work, expressing: *"I think most people, rightly or wrongly, decide who they are often by what they do. And if you don't do anything anymore... it's kind of difficult."* She expresses that she is no longer a "full human being" based on her inability to define herself outside of the workplace and the requirement that she justify her use of time to receive insurance coverage. Rather than Rose's initial efforts to maintain her full identity with minimal interruption from this

illness, we see her struggling to locate and salvage some remaining aspect of herself amidst the boundaries and interruptions that have limited her existence.

Rose emphasizes that these are choices she has made for the sake of others and she also presents her choices as she believes others perceive them. That is, she describes herself as having to explain these choices and explain her changing identity to others, more often than she discusses the impact on her self or perception of self. Similar to her attempt to distance herself from her seizures, she appears to distance herself from the growing “epilepsy self” being restrained by these boundaries. While this again enables Rose to perceive a greater sense of control over her identity transition as a whole, this maladaptive coping strategy has been associated with higher likelihood of mood disorder in adults with epilepsy (Goldstein, Holland, Soterious & Mellers, 2005).

7.6.1 Building a safe nest. *Security is my biggest personal issue. While I know there is no security in the larger sense of life, we all try and set up little nests that we are comfortable within.* (Written narrative)

In her writing, Rose introduced the metaphor of *nests* in the context of a space that provided security and a certain degree of protection from the threats posed by factors related to her health. This image was a powerful one to me as it reflects the boundaries of personal space, whether psychological, physical, or social, that can take significant work to build yet is fragile in nature. A nest also suggests a home, a safe space that is often hidden and that houses only an individual and the supports that she or he trusts. When our conversation returned to issues of control and security, I asked Rose to elaborate on her nest. I wondered to myself: What does the nest contain? What exists inside the nest and what remains outside?

Me: *I was going to say- can you describe the nest to me a bit? What would it be?*

Rose: *It's when I'm able to be comfortable with, um (long pause)... I mean at least if you're working you have control over whether you're doing a good job or not, for the most part... So I had control over that but like, and work has often been the most part of my life, like the biggest part, or setting, whatever I was doing at the time was more important than my outer world. And certainly more important than the epilepsy. But now that outer world has... evaporated... and I've had to make do with, um, me.*

Rose's continued description was valuable in delineating the shrinking boundaries of her "nest" in contrast to the "outer world" that she appears to perceive as unsafe:

Just being able... the nest I guess is just being able to be comfortable for a moment. Like, whether it's that 45 minutes in meditation when I just spend 45 minutes doing nothing or whether it's, for me, 2 hours in the garden when I just spend time weeding, doing nothing else that I can't have control over, you know? Just being able to deal with that, and be happy with that.

For me, Rose's description of her metaphorical safe nest illustrates the need for security and control. Furthermore, the fact that these aspects are described as very brief periods of time (e.g., 45 minutes to 2 hours), we come to see that her safe nest is indeed a small actuality. What was once a brief interruption in Rose's life has become the majority of her days, with brief interruptions of safety, control, and the life she once knew. Her further description that the "*nest gets shaken*," repeatedly in reference to having to justify her current existence to the insurance company, helps us to comprehend the fragility of this psychologically safe space when she senses others' or her own questioning of this safe space and the limits of her own control over it. Rose's description makes it clear that she has difficulty being satisfied with this limited existence.

Despite her insistence on a desire to have others to rely on, as well as her dissatisfaction with an isolated life, Rose initially describes a nest that contains only herself. It is only when she

begins to elaborate on the “outer world” and on alternate aspects of the nest that we see her trying to establish a space where she can trust others.

Me: *What is the outer world?*

Rose: *Um. That’s um, the work world, the insurance world, um, I never know if doctors are part of that. I know most of them are trying to help but... you know, my GP says, “I’d just really like it if you were happy.” (Sigh.) So would I! (Laughter.)*

While she begins to draw her social boundaries early in life, these appear to become more restricted as she ages, sometimes against her own wishes. She described work as central to her life, but she now perceives “the work world” and the “insurance world” as external. She further questions the presence of her doctors, tentatively stating that “*most of them are trying to help but...*” This illustrates both the struggles that she has had with these interactions, as well as the concrete boundaries that she is attempting to establish by considering all doctors in or out of her safe space. Rose begins with a description of all of the people and spaces that she must exclude from her safe space; however, she does emphasize the importance of community and social relationships, particularly as she ages. She expresses that her “world is very small” and that she believes it is healthier to live with others when attempting to recover from a seizure. She is emphatic that the nest is not a “physical thing,” though she does refer to the safety of her own home and the money needed to live comfortably. When she does refer to her house or a shared apartment as possible nests, we come to see that the walls of these structures also represent the emotional and social walls of Rose’s world; the safe limits that keep trusted others inside her nest and untrusted intruders out.

7.7 Social Control and Medication: The “Fix-It” Attitude

My view on meds is the same now as it was then- “Fix it – I don’t feel right.” Actually, I think this attitude has stood me in good stead, but lately, I am realizing that I am nearing the end of the meds that are available to help me. (Written narrative)

Rose initially presents seizures as an interruption in her life, and one that she naïvely or optimistically perceives to be fixable or controllable through use of the correct medication. A medical diagnosis and treatment can provide security and help organize one’s meaning of the illness events leading up to diagnosis (Charmaz, 1991); however, Charon (2006) has argued that this can prove more disruptive when an individual experiences a symbolic loss of control over her illness narrative due to prescribed regimens. For Rose, this appears to be the case and appears to be even more disruptive when the biomedical and pharmaceutical systems she must rely on prove not to “fix” the broken system—her illness (Lakoff & Johnson, 1980; Kirmayer, 2004). Here, we are introduced to the early concept of the “fix it” attitude:

And I think, um, it stopped me from having seizures, don’t get me wrong but the meds that I’ve been on work, for the most part... until they don’t anymore. You know, they work for a long time and then they don’t anymore but the side effects have just been horrendous and uh... when I started having seizures, um, I knew what I should feel like. Physically, mentally... you know, I had a clear idea of what a clear-headed human being was like. So... I wanted to get off the phenobarb and you know, I don’t want to trip up stairs, I don’t want to be off balance, I don’t want to be... just feeling stoned all the time. Fix it! I want to be me again!

Rose emphasizes the transient nature of her success with medication in explaining that “the meds that I’ve been on work, for the most part... until they don’t anymore.” We come to understand the uncertain nature of her illness and treatment, in which she works with her

physician to identify the successful treatment — to “fix” the problem — only to discover that there is no permanent and guaranteed solution. Here, the passage of time is in fact a greater opponent than even the medications or the seizures that she is working to control. Rose uses multiple metaphors in describing her experience of side effects including “thick,” “stoned,” and the most powerful: *“I want to be me again!”* This last statement implies that the medications have such an effect that she perceives them to change the fundamental nature of who she is.

Kirmayer (2000) observes that individuals may adopt biomedical terminology and concepts, such as “fixing a broken system” in order to feel increased self-efficacy and control in their interactions with physicians. Nonetheless, he cautions that the patient and physician may have different meanings of this terminology. In the case of Rose, we could surmise that she has adopted the mechanical “fix it” metaphor in the context of her epilepsy; however, she frequently refers to the medications rather than the seizures as the broken part of the system. This is an example of an individual making use of the linguistic resources to which she has been exposed; however, there is a need to ensure that she and her physician both understand the elements that she perceives as broken, and those that she feels the need to control or “fix” (Kirmayer, 2000, 2004). Rose strives for control over her medications, sometimes portraying her physicians as collaborators with whom she works to establish an effective treatment. At other times, Rose emphasizes the need to self-advocate, when she portrays physicians as gatekeepers who may penalize her with the wrong choice or dosage of medication or may enable her to be medically stable without compromising her ability to work. These differing perceptions may be a consequence of different understandings and miscommunication between Rose and the physician:

Lucky enough to have been my own advocate. You know, I’m pretty pushy but... If I’m interested in my own medication and something’s wrong. You know, it’s me and my medication, so it’s difficult not to be involved. I really feel- I feel really bad for the people

who aren't able to be involved. I find that, you know, very upsetting how overmedicated people can be.

Given her repeated reflections on past solutions and new complications that continued to arise, I asked Rose to describe her current medications and seizure status. She responded in an exasperated and sarcastic tone, explaining that her physicians use technical terms rather than speaking to her in personally meaningful terms. Despite what Rose presents as a strong stance and a formal boundary as the “fix it” advocate, it is clear that she feels limited by her physicians and by the medications available. Of interest, she herself frequently uses medical terminology that she has appeared to gain comfort with, for example, expressing frustration that she has a better understanding of her own blood levels (i.e., therapeutic level of medication in her blood) than a nurse. She reflects on the technical language that her physicians used to describe her seizures and her as a patient:

Well-controlled. “As you’ve only had X number of seizures, we consider you well-controlled.” Rather than... I’m in a slot now. You think having multiple seizures every year is well-controlled? Thanks! I consider myself Rose, but thanks! That’s what I’m looking forward to? Okay. And all the side effects, whatever, doesn’t matter. “That’s our goal, and you’ve hit it.”

Here I witnessed Rose’s sense of frustration and defeat as she identifies the labels that she has been given rather than her name. She also expresses dissatisfaction with the current level of treatment, with the perception that physicians might have reached their end point in terms of what medications they are willing or able to provide. Rose describes that both she and her physicians feel that she is “*kind of running out of meds to try out so that’s a little concerning.*” In this statement using medical lingo, we are confronted with the temporal reality that she has possibly “*run out of [treatment] options.*”

Consistent with Rose's experience of aging, she describes the fear of reaching a point over time where she can no longer ask the doctor to "fix it." Not only does Rose seem to experience a change in the medications to "fix" her illness, but she also experiences an ongoing shift in her ability to maintain the behaviours that enable her to advocate for herself. Initially, she is the one in charge of managing her own medication, both with physicians and at home. However, she describes a fear that a loss of control over her self will lead her to lose control over her own treatment choices:

I watch people age and the seizures for me have changed as I age and hormonal changes seem to be a big change for what goes on in the brain. As I change and have less control over me, then the "fix it" attitude is not going to be in my control anymore. You know, people will just give me the meds that they want me to use. And that's frightening to me.

Rose emphasizes the fear in others giving her the medication they choose without asking for her input or approval. She fears losing control over the "fix it" attitude, the role of self-advocate and self-mechanic, if she reaches an age or stage where she is no longer able to demonstrate that she can live safely and responsibly, taking her medications as needed. This leads to another narrative structured around those who she sees aging, and the increased need to find people who she can trust to exist in her safe space, and to help her maintain control:

Rose: I met a woman who's in my mom's nursing home, who's about my age actually, just a little over 50 she was I guess, so a little older than me... and her son had put her in a nursing home because she'd had seizures and she'd fallen on her driveway and she was missing teeth and stuff and her son couldn't take care of her and she wasn't able to take care of herself- make sure she was taking medications, right?

Me: Mm-hmm.

Rose: *So, part of taking care of yourself is making sure you're taking your meds and so, if you don't have people around you making sure that you're taking your meds when you're not well or coming out of a seizure then... that's not a nice thought.*”

Rose's concern over her ability to control her self, including her seizures and her medication management, is an aspect of her identity that she has been trying to address. She explains that she has come to rely on a trusted neighbour, whom she refers to as her “friendly drug pusher,” to check in with her on a daily basis to ensure that she is meeting her health and medication needs. Again her narrative is told from the perspective of an individual who is both fearing and facing the consequence of age, as well as grappling with control and the need to distance herself from the reality that she may lose this person to rely upon. Nonetheless, she holds on to the comedic tone of the “friendly drug pusher” and describes informal terms that she uses with him in an attempt to avoid directly addressing her health and her need to rely on him.

7.7.1 Social control and medication: Loss of self to the medical identity. We can see a progression over time where Rose continues to express a lack of control, with the boundaries closing in further beyond her control when she is restricted by decreased seizure control, accompanied by increased restrictions on her activities. Rose expresses the feeling that at times she feels she has no control and no choice over the limitations that epilepsy has imposed. There is another temporal element here: in contrast to her early days in which she attempts to ignore epilepsy and continue with her defined career and life course, Rose now appears to be faced with epilepsy as having “*taken over my life.*” Her identity has shifted from one in which epilepsy is held entirely external if not ignored completely, to an identity in which epilepsy is so central that Rose has difficulty finding and defining her self at all. She states that “*it's the regular that happens in my life*” since she was forced to leave her job. She is unable to define who or what else there is in her life:

Rose: *It's more a basis of life than I'd like to think. So that's what really came up... was that... I don't like to think of epilepsy as running my life but... it seems to be... at the moment.*

Me: *And so... how do you feel that it's running your life?*

Rose: *Um-m-m... I'm on long term disability because of epilepsy, so I'm not working anymore. Um. Meds at least twice a day. Um... I've got people calling me to make sure that I take the meds and that I'm eating and um, seeing doctors very regularly and um, ya. It just, uh, it seems to be what orders my life now cause there's no job, no... it's the regular that happens in my life, not that I've had seizures regularly, thank goodness, but all the stuff that goes around with it.*

In contrast to the boundary that Rose once created between herself and her epilepsy identity, even the tiny nest that she is struggling to defend now appears to contain her epilepsy; she describes the fear that her medical identity has “*taken over my life.*” This seems like a strong contrast to the life in which she attempted to ignore her condition entirely, as she now experiences a life in which she is entirely defined by her condition. Here, Rose expresses her resentment for the way in which epilepsy has taken over her life. Reminders of the central role that epilepsy has come to play vary from the daily rhythm of medication to monthly calls from a nurse. She describes her hospital visits as punitive experiences that were a consequence of her having seizures and were against her control. Each instance in the hospital is described as an instance in which explanations are lacking, thus leaving Rose feeling further out of control and vulnerable.

We again return to the theme of an “*ultimate loss of control*” when Rose describes an assessment to see if physicians can control her seizures beyond medication. Rose undergoes this assessment to see if surgery is an option. She describes disappointment in finding out that surgery

was not an option. While she identifies the experience as a whole as disappointing, the focus of her narrative seems to be on the trauma of the assessment process, as she describes waking up from her surgical assessment tied down with a leather belt across her chest:

Me: So what did it feel like to wake up that way?

Rose: Terror. Cause there was nobody there and I was strapped down. I remember seeing in a hospital people who had been lined up for shock therapy and they had been- back in the day when they did tie you down with leather- I mean they had the same, I had seen the same belt on these people. They were lined up and their hands and their legs were tied down, and they were just- you could see it in their eyes- and ah... that's what it felt like. I mean, it's bad enough not being in control of yourself but that's the ultimate not in control of yourself. Yikes, it was a frightening experience.

Rose describes this as punitive and explains that she felt terror, and goes on to relate it to a memory of seeing individuals in a hospital lined up to receive “shock therapy” or electroconvulsive therapy. Her association with this memory seems to indicate a body that is entirely at the mercy of the biomedical system, as though a doctor or external source has full control of the individual’s body, and indicates that this experience is perceived as punishment rather than aid (Charon, 2006). Further, Rose’s association with individuals who are receiving shock therapy insinuates that Rose might interpret her experience as a prisoner in which her uncontrollable physical experiences might lead her to be treated or questioned for her psychological state. Rose also recalls the memory of being “*strapped into an ambulance when you don’t know what’s happening,*” again conveying the sense of helplessness that one can experience physically and psychologically in the context of medical care during the disoriented state following a seizure (Radley, 1994).

7.8 Conclusion: The Last Boundary

Rose perceives the evolution of her identity as she ages. While she spoke of herself as a young woman, diagnosed and able to live without acknowledging that epilepsy existed in her life, she now sees herself heading towards an identity in which epilepsy has taken over her life, her physical and social identity. Rose expresses this loss of identity in the eyes of “bad doctors,” for whom the condition is equivalent if not more relevant than her identity as a person. She explains they “*were more interested in the condition than the person.*” Her resentment of having her identity consumed by her illness is illustrated in her resistance to wearing a medic-alert bracelet. Rose’s stance against wearing a medic-alert emphasizes the fact that this visible label would be the last boundary, the last aspect of her identity over which she has control. The powerful stance against this label illustrates her desire to control something that threatens her safe space:

But. I’m, you know right now I don’t even wear a medic-alert... which is really, I know, not... I don’t know. I just don’t feel like being tattooed. There was that comment that some people are tattooed and I thought, “Well that actually I could, you know, probably handle a tattoo. It would say DNR on my chest.” Umm... but... it makes it easier for other people, it doesn’t do a damn thing for me. Wearing a medic-alert.

This striking statement, particularly Rose’s strong and sarcastic, “*It would say DNR on my chest.*” illustrated for me her level of exasperation and hopelessness. Not only is she strongly opposed to having a visible marker of her illness, she is even more opposed to a future where her condition worsens. Such a future is perceived as her world continuing to shrink, leaving her so far out of control that she would rather not continue to live. Rose goes on to defend her stance and illustrate the way in which she continues to build a safe “*nest*” rather than completely surrender to a visible marker of her illness. She offers that she would rather live in her safe space, in the nest that she has built than exist in public with this marker:

If I'm alone at home and have a seizure then it doesn't matter but... nobody is here to- and nobody around me- like, my neighbours know, my friends know... if I'm walking down Broadway and I have a seizure then... like I have one and I'm just getting a coffee. (Pause). Who's it for? You know?

Despite Rose's statement that she is opposed to openly sharing an epilepsy label, she is acutely aware of the necessity to share information regarding her condition when care is needed. She makes this clear by outlining the various locations (e.g., wallet, fridge, neighbours, etc.) that she has positioned detailed information regarding her condition and her treatment approach (i.e., pill colour). According to the medical typologies of epilepsy developed (Schneider & Conrad, 1983; Kirchglässer, 1990) and more recently confirmed (Kilinc & Campbell, 2009), Rose could be considered to have adjusted to her epilepsy but to hold a primarily pragmatic identity, in which she controls when and with whom she is willing to share her illness, perhaps to let others into her "nest," and this is often only when necessary. Importantly, while Kilinc and Campbell (2009) emphasize perceived stigma as playing a central role in one's resistance to sharing a diagnosis of epilepsy, it appears that Rose's perceived loss of control over her own identity has been more central. We must therefore accept that the medical typologies of epilepsy cannot be held as a static interpretation, but rather a fluid spectrum that might change not only with adjustment to illness, but also over one's life course (Kilinc & Campbell, 2009; Kirchglässer, 1990; Schneider & Conrad, 1983). For Rose, her introduction to epilepsy as a family secret may have impacted the level of control and secrecy that she perceived necessary. This interpretation is supported by metaphorical references to her early desire to obtain medical control (i.e., "fix it") and social control (i.e., social boundaries of her "nest"). Her social transitions over time, both at the psychosocial and biomedical level, may also have coloured her perceptions of social control and the primacy that it came to hold in epilepsy experience.

Rose's narrative provided some diverse perspectives on the family relationships involved in conceptualizing epilepsy from early diagnosis. While Grace too had input from her family with her diagnosis, she in fact had been experiencing seizures well before this diagnosis and the related social interactions took place. For Grace, she appeared to focus her narrative on the relationship between her physical self and her epilepsy. While Rose experienced seizures that involved complete loss of physical control, Grace's seizures began with minor losses of awareness or physical control and yet these were the moments that became the focus of her relationship with epilepsy and her epilepsy narrative. Let us turn our attention to Grace.

CHAPTER EIGHT

Grace: Listening to the body

8.1 Meet Grace

I knew Grace through her involvement with the local organization for epilepsy, and when I mentioned my study she was quite open and interested in sharing her experience with epilepsy. Grace was a 42-year old woman who lived with her husband and two-year old son. She had worked as a nurse in cardiac intensive care for almost 20 years. While she clearly prided herself on her education and career, we discussed how this had been a change of course from her teenage love of ballet over academics, a change that was prompted in large part by seizures which began at age 17. At the time of our meeting, Grace had not had a seizure in about 20 years. Not only did Grace provide insights regarding her own experiences with epilepsy, but she also provided insights from having been involved with the community organization for over 25 years.

A week after we had met and had a brief conversation about the study, Grace sent me a written narrative with a disclaimer at the top:

This is long and rambling. However, I thought it might work better if I didn't attempt to censor things too much and just saw what came out. (Written narrative)

This disclaimer seemed to reflect Grace's attitude in both her written and oral narratives, as she candidly introduced and responded to a variety of topics related to her epilepsy experience. Similar to others' written pieces, she provided an organized and chronological series of events; she included events that were notable due to ongoing struggles as well those that indicated a perceived overcoming of an epilepsy-related obstacle. Grace provided narratives that covered her life as a whole, offering insight into which events occurred despite, because of, or regardless of the presence of epilepsy in her life. This comprehensive narrative made it clear to me that

epilepsy played an important role in Grace's identity as a whole. She also suggested that I speak to her father, who had experienced epilepsy in his youth and who had introduced Grace to the local organization for epilepsy when she was first diagnosed.³

Grace requested that we meet in the on-campus interview room of the Qualitative Research Centre. When she arrived she described memories from walking the hallways, back when she had been a student many years ago. My interactions with Grace were very positive; our conversation involved many giggles and light-hearted jokes as she reflected back on different aspects of her experience. It seemed obvious that she occasionally used humour to put herself at ease, but she generally appeared comfortable discussing her memories including some difficult topics. Both her self-description and my impressions were those of an assertive woman who was in control of her life. Given her training and work in the health care system, Grace had a tendency to provide impressions from both the practitioner and patient side of her medical interactions. She also used terminology that might have been less accessible to someone outside of medicine.

³ Grace's 70-year old father, Alfred, provided me with a handwritten narrative of his major life events amongst which the past occurrences of seizures in his teenage years was a minor detail. I met Alfred in his home and conversed with him for about 45 minutes, after which his wife joined the conversation. Alfred was willing to discuss his experience with epilepsy but provided minimal responses (i.e., often "yes"/"no" answers) to my attempts to open the dialogue. He explained that there was little discussion regarding his seizures when he was first diagnosed, and that his parents and family physician discouraged conversation. Alfred was advised not to disclose his history of epilepsy in applications to professional school, workplace, insurers, and he did not inform his wife of his condition until several years after they had been married.

Because Alfred's interview took place after Grace's, I was able to probe with reflections from Grace's interview and I have included relevant passages regarding his role in Grace's experience. This provided me a different perspective of Grace's epilepsy, one that was informed by a parent who had experienced epilepsy himself. This afforded me the opportunity to consider language and conceptualizations used by Grace and Alfred that might have contributed to a shared meaning-making process. I treated Alfred's interview as information that I collected after the formal oral interview, in the same way that I treated other follow-up material (i.e., follow-up conversations, emails, etc.) that I had with other participants.

8.2 Epilepsy As a Loss of Physical Control

The primary metaphors and overarching themes of Grace's narrative can be seen to emphasize physical control as central to her epilepsy experience. Control surfaced most frequently in metaphors and narrative sections referring to her physical world and physical control. Given that people's conceptual system is grounded in interactions with our physical environment (Lakoff & Johnson, 1980), embodied language is identified in many if not all narratives. Nonetheless, Grace's use of physical terminology was even more prevalent than any other participant, as she grapples with the external forces that impact her physical actions (Schwabe, 2008). Grace's narrative also involves a level of secrecy surrounding her early seizures; she demonstrates a need to be perceived as "normal" in the eyes of family and peers, which is reinforced by interactions with the medical system. Here, we will explore her perceived stigma regarding less visible seizures to a transition involving the empowering nature of visible seizures and an epilepsy diagnosis. By the end of her narrative, she has evolved from a confused teenager to a woman who achieved control over her seizures; she has shifted from a retrospective account of her early seizures and reliance on her father to an empowered woman who demonstrates for her father how to talk about epilepsy. Grace's narrative ends with a return to questions regarding physical and social control, as she is confronted with a new chronic illness that challenges her to re-assert herself in struggles with her identity as a patient and professional.

8.3 Grace's Seizure Stories: "Threatening the Status Quo"

In reflecting on Grace's seizure experiences, her struggle against an external force maintains the theme of physical control. While the primary focus of Grace's narrative appears to be her physical self, her seizure experiences provide multiple narratives in which we observe concerns regarding both physical and social control. These trajectories are similar to

Kirchglässer's (1990) lay theories of epilepsy that individuals use to make sense of their experience. Grace's initial approach is similar to the "life-world illness theory," involving seizure descriptions as Grace tried to make sense of them prior to her disclosing her seizures. A second biomedical trajectory, almost identical to Kirchglässer's "medical illness theory," involves Grace's descriptions and interactions with the medical system in which her neurologists play a central role in meaning-making. A third public trajectory, similar to Kirchglässer's "mixed-illness theory," is Grace's conceptualization based on descriptions of seizures that others observed, medical terms that she feels adequately express her experience, and her own interpretations that have involved attempts to both dismiss and eventually discuss these experiences.

8.3.1 First seizure narrative: "It would go away." Grace's initial trajectory involves descriptions of her less visible seizures, which she attempted to minimize and did not share with other individuals. She first identifies "absence seizures," which she describes as a "*flash before my eyes*." Grace emphasizes that these events were brief, occurred only in the morning, and did not interfere with her classes. It appears that the pattern of this occurrence as well as the lack of visibility, occurring every morning before 8:30 a.m., enabled Grace to perceive these seizures as less intrusive. Further, the "it," this external flash of light, was something she externalized as not part of the Self or body. She chooses not to name this "it," partially as a way to distance it from her self. We can hear at this early stage her attempt to minimize the events and rationalize that they did not detract from her ability to keep up with what she needed to do:

It was always in the morning and it would go away and... you know, it never really seemed like much initially. It would be, um... just sort of a flash before my eyes. And just so brief and... I remember sitting on the stairs at school waiting for the 8:30 bell to ring

and having that happen but you know by 8:30, I think it always had stopped. You know, it didn't interfere with actual class time that I can recall.

These minor distractions that only she was aware of became more noticeable when she interacted with others or was attempting to perform actions, in which she identifies “*constant interruptions in my train of thought*” and medication side-effects that lead to her inability to participate in a dance recital. Grace focuses on the impact of this external entity on her ability to coordinate her disciplined physical activity that used to come with ease (Radley, 1993; Scarfe, 2014). She describes this interruption in her ability to dance as a confusing and disturbing time that was shortly followed by the occurrence of the first seizure during which she lost consciousness, her first “grand mal” seizure.

8.3.2 Second seizure narrative: “It’ll stop.” In establishing Grace’s first seizures and diagnosis, she expresses uncertainty as to when these experiences began. She reflects on the confusing experience when one is not aware of what constitutes a seizure, as well as when one is not aware of when a seizure has occurred. Grace describes instances that she does not choose to disclose so as not to draw attention from others, as well as instances that she does not have the ability to disclose given that she does not understand or recall them. *At what point does an individual decide to “threaten the status quo?” How does an individual decide when their “invisible illness” suddenly becomes a “visible” one?* In her second seizure narrative, we see how Grace is forced to recognize that she may not have control over these decisions, as these “little” disturbances become more intrusive, her seizures become more visible, and she loses the option of not discussing them.

Grace: *So... the morning before I had my first grand mal seizure... I was, you know, having some of these seizures and so I'm just telling myself, you know, "It'll stop, it'll stop, and..."*

Me: *What was "it" for you? You kind of say "it"?*

Grace: *Ya, it was kind of those... those little flashes and, you know, the little twitches... cause at the time it was just little twitches, you know, it wasn't sort of a full out jerk. So ya... I think some of it was maybe just my personality, you know, I just... I tended to be very quiet, I could be very secretive, I... um... ya, I just wasn't very forthcoming about things. And so ya, I think maybe if I were to have said something then it would have meant that something was wrong and I would have to acknowledge it. Well, you know, I didn't want... Who wants to acknowledge that something strange is going on with them? (Laughter). Ya, you know 'cause... it obviously was a threat somehow... you know, at the time maybe I didn't perceive it as a threat?*

Me: *Ya.*

Grace: *But you know it was... just threatening to... it was threatening the status quo and I didn't want it to. I wanted to keep on the way I was... And ya, eventually I had to face it and, ya, so that was the way it was.*

Grace's perception of this unknown threat would be consistent with that of an external entity that she perceives to be interfering with her ability to control her own actions (Schwabe, 2007; Surmann, 2005). Nonetheless, she feels responsible for these actions and explains her logic retrospectively:

Well, I'd been having seizures and not knowing it. Because I was having myoclonic jerks and little absence seizures and... never said anything to my parents because, you know, of course if I say something to my parents, then something's wrong.

Grace's statements make it unclear as to whether she was truly unaware of her seizures or whether she preferred not to acknowledge them for fear of "it" becoming a reality and perhaps a norm for her daily life. While she recognizes some awareness of these events, it is only in retrospect, once she is given the medical language with which to define her experiences, that she is able to explain what was occurring (Kirchglässer, 1990; Zaner, 2004). Nevertheless, even if she lacked the terminology to define her experiences, her statements seem to imply that she would prefer not to disclose her seizures for fear that, once acknowledged, her experience would gain more power and become a part of her reality.

8.3.3 Seizures: The invisible bully. Grace continues to describe the impact of epilepsy in the context of its impact on her ability to carry out daily activities, explaining that her limitations increased in severity over time as she began to experience "myoclonic jerks." These instances involve minimal agency, and suggest instead that Grace is at the whim of an external entity (Surmann, 2005). Other memoirs describe a similar experience of an external entity controlling one's motions, such as Slater's (2000) description of herself as a "marionette" being controlled by a puppeteer. For Grace, she continues to focus on the physical implications of her seizures on her ability to dance. She describes her early "myoclonic jerks" in a way that separates her body parts from her dancing self:

I couldn't really enjoy dancing, you know, because I'd be dancing and suddenly [throws her hands up] ... I would just land straight-legged. You know, I'd be jumping and then suddenly my legs would just lock, it would be crazy.

Grace describes her Self as dancing (i.e., "I'd be dancing" or "I'd be jumping") with a sudden shift to her limbs as the element that was out of her control (e.g., "*my legs* would just lock). Not only does this separate her Self from her own body, she identifies no warning or awareness of

when she might lose control. In describing her myoclonic jerks, Grace most frequently describes the way in which her limbs act independent of her body or mind. As she describes more “violent” seizures, she conveys it as though an external force is acting upon her and her body (Schwabe et al., 2007). Grace describes her movement as not initiated by her body but rather as reacting to an unknown “it.”

You know, they could be violent even though they were brief. So, you know, if I was standing up, I could just get thrown to the floor. Or you know, if I was sitting down I'd just kind of jackknife and just kind of hinge forward at the hips.

Grace's way of making sense of these more physically violent instances is by entirely separating the Self from the epilepsy experience, the “it” that is acting on her body. This is consistent with Surmann's (2005) early findings, particularly as they relate to individuals experiencing more violent physical seizures. Grace recalls her “grand mal” seizures as entirely out of her control and instead recalls details reported by observers, as well as injuries that she acquired: *“I have suffered broken teeth, a broken nose, and have had numerous falls.”* The metaphor of “battle” against illness is one that has frequently been identified in illness narratives (Kirmayer, 2000; Lakoff & Johnson, 1980; Teucher, 2003), and this mention of “battle” was also seen in Grace's narrative. In addition, the previous passage suggests a variant of the battle metaphor. Grace's descriptions are similar to Kissing's (2003) “bully” metaphor, in which she describes her body turning on her the way that a bully would target a child in the playground. Both Grace and Kissing (2003) describe themselves as being bullied by their own bodies, in that they report losing a fight for which they were unwilling, unprepared, and not consciously present. Grace recounts a “grand mal” seizure based on a classmate's report:

I just wandered off and started saying, “B-b-b...” and you know, she's trying to just... you know, kind of trying to just figure out what I was doing, what I was trying to say, she

said, and then I just... fell to the ground and started having a seizure. So... ya... any of the witnessed tonic clonic seizures people would kind of fill in things.

Grace highlights her lack of consciousness and absence of the Self by relying on others for support and to help her make sense of the seizure experience. While her parents played this role early on, it was often high school friends who came to “fill in the blanks” as she attempted to make sense of these foreign experiences. Grace’s acknowledgement of this necessary co-construction of experience is yet one more illustration of her helplessness during her seizures, as others observe a physical fight for which Grace is not consciously present. She recalls how her own lack of presence had been problematic at times:

I guess since I didn’t remember the seizures it was kind of hard to... accept it in some ways. You know, how could I be having this thing that I had no recollection of? And, I’ve never heard of before?

Grace’s lack of presence or lack of consciousness in the moment of the seizure made it difficult to initially acknowledge, then accept, her experience. In numerous epilepsy narratives authors rely on witness descriptions, given that the individual with epilepsy is not consciously present for the event (Räty et al., 2009). For individuals to whom epilepsy is unfamiliar, it can be difficult if not impossible to acknowledge a seizure, let alone an illness, with no evidence apart from the reaction of others (Jacoby et al., 1996; Räty et al., 2009). With most illnesses, a physical symptom provides evidence that something is wrong, whereas a seizure does not always leave evidence unless there is visible movement of the body or a noticeable loss of consciousness is involved (Angus-Leppan & Parsons, 2008). A brief seizure from which one emerges with no change in her physical or emotional state can be even more difficult to remember, let alone acknowledge. As Grace points out, she had not heard of the seizures she was experiencing and thus could not comprehend how she could be “having this thing.”

8.4 Diagnosis: Hearing the Un/Spoken

As noted earlier, Grace's narrative took different forms; one she told chronologically, in the order that she experienced the progression of her seizures despite her secrecy surrounding these events. Another narrative she described in the order that her physicians conceptualized and diagnosed her narrative, first identifying "tonic clonic" seizures and seemingly working backwards until an accurate diagnosis and treatment had been established (Frank, 2010). These two narrative timelines impacted Grace's descriptions of her treatment and diagnostic course, which seem intertwined with her own understanding of her seizures, similar to Kirchglässer's (1990) mixed-illness model:

So, you know I saw my family doctor and it was still very much a jumble and I soon saw a neurologist and so then it was okay. Now I had this thing called epilepsy... whatever that is.

As with many narratives, being given a diagnostic label allows comfort in that there is a medical explanation, or at least a medical title, for the event (Kirmayer, 2000; Zaner, 1988, 2004).

Nevertheless, despite being given a label, Grace quickly highlights the limits to the comfort of a label for which we may not have an explanation:

And then... you know, to be told, "Well, you're having seizures and we don't really know why..." And... so ya, it just kind of feeds into that whole uncertainty, that unknown, and lack of control and everything, it's like ya... you don't seem to know much at all.

Grace describes her own shift from a state of confusion and minimal understanding regarding her invisible symptoms, until she was given a diagnostic label of "epilepsy." Notably, this diagnosis and Grace's subsequent understanding of her condition occurred only after her first witnessed, physical seizure. Multiple researchers have identified this stage in which individuals, experiencing an invisible illness, experience the relief of a diagnostic medical label (Kirchglässer,

1990; Nijhof, 1998; Snape, 2015). For Grace, this label only partly legitimized and normalized her physical actions and experiences, based on the “epilepsy” definition given by her first two neurologists as the occurrence of “fits” or “grand mal” seizures. She emphasizes that no one had investigated or acknowledged the other types of seizure that she was experiencing as part of her epilepsy, despite her own descriptions, until she was seen by her third neurologist. Grace’s struggle to find an accurate diagnosis and treatment also illustrates the different language to which she was exposed, and that may have impacted her current conceptualization of her epilepsy.

8.4.1 Neurologist One: Fits and electricity. Grace explained that her first neurologist used the term “fits” to refer to her grand mal seizures, identified as the most severe type of seizure terminology used in the British medical community by Plug et al. (2011); this term is minimally used in the Canadian medical system. She stated that his sole priority was to control her “fits,” and that he “didn’t care to listen” to her reports regarding other seizures and medication side effects that she was experiencing. Grace’s interactions with her first neurologist, at age 17, offer a powerful illustration of the role of language in a patient’s attempt to gain an understanding of her illness:

Well the first guy was ah... English. So he said I had fits. And.... Um... you know and he gave me the basic lecture of how the brain works- you know, neurons and, uh... that sort of thing, you know, how they use electricity.

It is of interest that the only time in which Grace uses a reference to seizures and electricity is following a “lecture” on the topic of neuronal use of electricity. She discusses the seizures that she experiences while taking the first medication prescribed by this neurologist:

I remember walking up the stairs in my parents' house and the only reason that I wasn't catapulted backwards is because my dad was standing there. Cause you know, it's just like being hit by uh, a lightning bolt. And, you know, so there I am just jerking and twitching all the time and... he's [neurologist] not returning my mom's phone calls. And when he does, it's just like, "Well, that's the nature of her epilepsy."

Not only does Grace repeatedly refer to her seizures as caused by an external agent, in this instance she identifies the external agent as electrical reactions to the medication she has been prescribed (Schwabe, 2008). She explains these seizures in the *electrical* terms that were used to explain seizure occurrence to her by the prescribing physician. She describes seizures in which she was “catapulted backwards” as though she was “being hit by... a lightning bolt.” This is an illustration of the way in which an individual may rely on a physician’s explanation to make sense of her experience, or to re-frame her experience in a manner that is consistent with her explanatory model (Zaner, 2004). In this case, Grace maintains the concept of an external agent causing her seizures, with the external agent identified as electrical disturbances prompted by what she thought were inappropriate medications (Schwabe, 2008).

8.4.2 Neurologist Two: Seizures and “the other stuff.” In regards to this first prescribing neurologist, Grace identifies that she “*learned not to trust him,*” based on a dismissive attitude in which he “*does not listen*” to her concerns. Grace implies that she ties her level of trust of her physicians to their degree of respect for her, as demonstrated by their ability (or lack thereof) to engage in an equal conversational exchange. While she portrays her first neurologist as not interested in hearing what she has to say, she characterized her later interactions by becoming “equal partners” in the conversational and diagnostic exchange. Grace expresses increased trust associated with her second neurologist, focusing primarily on the fact that he was someone “*I thought I could trust... you know, someone I could have a conversation*

with.” Nonetheless, she expresses disappointment in that neither of these first two neurologists inquired about concerns or symptoms beyond the control of her tonic clonic seizures:

Grace: *The [second] neurologist, mmm... I don't recall us discussing things too much.*

Uhh... it was just, I think he probably just called them seizures, he would call them seizures. And we never talked about the other stuff at all...

Me: *What was the other stuff?*

Grace: *The absence and myoclonic jerks.*

Me: *Okay/*

Grace: */Never talked about them at all, never. No... and... it was kind of just like, you know, “How are you doing?” It was always, the focus was always on if I had had any grand mal seizures, that's always what the focus was on.*

In describing her interaction with the second neurologist, Grace describes her seizures as referring to “grand mal” seizures and “stuff” in reference to all other seizures. This trend of considering only severe seizures as deserving of the “seizure” label and treatment is one noted in transcripts of other participants, as well as in reviews of public information, and misinformation, regarding what constitutes an epileptic seizure (Krauss et al., 2000). Grace comes to emphasize, with frustration, the stance of the neurologist: “... *he never once said that my myoclonic jerks and these absence seizures were seizures. No one. Until Dr. Donat said those were seizures. No one.*”

Grace's narrative indicates that she did not openly disclose any abnormal events until she was witnessed having a tonic clonic seizure. She describes this hesitancy based on the fact that acknowledging it would mean that “something was wrong,” which is consistent with numerous published narratives (Hawthorne, 1992; Hawkins, 2013; Kissing, 2003) as well as medical reviews (Baker, 2002; Jacoby, 1993). I would argue that interactions with the first two

neurologists, in which Grace did not disclose seizures or events apart from her tonic clonic seizures, reinforced for Grace her already present belief that her other seizures (previously described by her as “little” jerks or “brief” flashes) were a lesser priority and were not something to discuss with others (Kirchglässer, 1990). In regards to Grace’s variable diagnoses and her reactions to these diagnoses, it is helpful to consider that “labelling is not a one-way process from doctor to patient, but a complex, interactional negotiation with doctors and patients as participants with equal stakes” (Plug et al., 2011, p. 19).

8.4.3 Neurologist three: Getting “on even footing.” Grace stresses that her first two neurologists focused only on her “grand mal” seizures, both in language and in treatment. She emphasizes that Dr. Donat, her third neurologist and the first doctor who she chose to name openly, was the first doctor who identified and diagnosed her absence seizures and myoclonic jerk seizures. Grace explained that these were the earliest and more frequent seizures that she experienced, and as such she described how they were more disruptive to her life. Indeed, much of her narrative focuses on these seizures, partially because she does not consider herself present during her tonic clonic seizures. This emphasis lies heavily on the physical and conscious nature of these seizures, and directs us again to the physical approach that Grace takes in describing her seizures and their treatment.

Grace describes feeling respected by Dr. Donat. Her statement: *“I was the one with the epilepsy after all,”* is telling in that it indicates a sense of authority and knowledge based on her experience of the illness as a patient, rather than based on a physician’s knowledge of illness acquired through study (Plug et al., 2011). Grace highlights his ability to listen and that rather than trying to “answer” or “label” her experience, he did not try to tell her what she was

experiencing. She emphasizes in physical terms, the way in which she had reached a level worthy of respect and worthy of being “a partner” in her own treatment:

Grace: *I remember I was asking him a question and he had either... I think it was a JURSI with him and... she started to answer and... he kinda said, “No, no, no... she has a Master’s in physiology. You don’t talk to her that way.” And... so... it just very quickly set the stage for- it made me feel like I was, you know, right on an even footing. You know, that this was sort of my partner in my treatment and, um... that I was respected. You know, I was respected for who I was.*

Me: *Mm-hmm.*

Grace: *And, um, ya. That just set the stage for, you know, the whole... um, relationship that we had. Cause, you know, I think it would have been difficult for me to think poorly of him after that.*

As with her introduction to her seizures, Grace again can be seen to return to metaphors regarding the physical nature of her experience, relying on metaphors of dance and physical performance to describe her positive relationship with Dr. Donat. She describes a consultation in which he demonstrates respect for her education in physiology, placing them on “even footing” and stating that this “set the stage” for them to become partners in treatment. Finally, she points out his focus on her autonomy and her expertise, empowering her to not only be treated as an equal but as an expert on her own condition (Baker, 2002). This is something that Grace emphasizes she was striving for with her other neurologists but that she did not experience.

8.5 Physical Control: A Body “Consumed”

The loss of physical control is a primary focus in both published epilepsy narratives (Hawkins, 2013; Simkin, 2010) and epilepsy narrative research (Brosh, 2011; del Vecchio Good

& Good, 1994; Scarfe, 2014). I refer here to a loss of physical control over one's body during a seizure, as well as one's perceived loss of physical control in daily activities. A focus for Grace's narrative is her physical self and her physical control, which I suspect was due in part to her focus on a disciplined body in the study of ballet at the time of her seizure onset when she was a teenager: *"I took my body for granted, I... was, you know, really consumed by ballet."*

Grace's experience highlights how a loss of physical control, most notably as it relates to her ability to dance, was the primary manner in which she defined her epilepsy experience. In describing herself as happily *"consumed by ballet,"* she suggests a level of trust in which she feels safe allowing this other entity to dictate her physical actions (Lakoff & Johnson, 1980; Schwabe, 2007). While she does not describe being consumed by epilepsy, Grace similarly treats epilepsy as another entity that is controlling her physical actions, although with epilepsy it is without her consent. Grace's comment suggests that it is safe to lose control to music and her dancing self, but not to epilepsy and her physical self during seizures. This conceptualization of an external entity, either as threatening one's volition or as entirely overtaking the individual's actions, has been identified as a common conceptualization in patients with epilepsy (Schwabe et al., 2008). Grace appears to mistrust epilepsy's impact on her physical movement and lacks any feeling of safety, questioning: *"Why couldn't I make it stop?"* The impact of this experience is captured in Grace's statement, *"I took my body for granted,"* which suggests that her loss of physical control is perceived as equivalent to the loss of her body as a whole (Schmitt, 2005). The statement emphasizes her need for physical control in both dance and in daily life, a need of which she was unaware until it was lost to her epilepsy.

A further addition to this concept is Grace's reflection on returning to dance in her early 20s, after medical treatment was able to control her seizures. Her retrospective view suggests that

she has gained awareness and appreciation of the privilege that she had in losing her physical self in the music in a way that epilepsy had threatened:

And so to... be able to return to dancing I appreciated it in a different way. Um... you know, it was something that was for me and um, I enjoyed the music and the movement. I guess there's also, you know, the rush you get from physical activity and, when I just would get totally lost in a way that I never really appreciated as a teenager and uh... you know, I just totally lost myself in it and I just... I just loved it.

While Grace experiences numerous challenges when her epilepsy begins, she repeatedly considers its impact in the physical realm. Her description that she would “*get totally lost*” in dance is similar to the experience of being consumed or giving control to another entity. I heard similar references from other participants in terms of the battle to regain physical control and trust their body, and this is indeed a common theme in illness narratives (Radley, 1993), and epilepsy narratives in particular (Jacoby, 2015; Schneider and Conrad, 1983; Scarfe, 2014). Hannah, another participant, describes learning to trust her body, in order to “let go” of control and enjoy physically intimate encounters. Grace identifies her compromise as acknowledging a lesser control over her body, to instead focus on her academics and employment. Nonetheless, both Grace and Hannah stated that they struggled with this acknowledgement of incomplete physical control, leading to an ongoing “battle” against their illness and, to a certain extent, their own bodies.

8.5.1 Physical control: Battling an external entity. In their research involving patient-physician discourse in epilepsy, Schwabe and colleagues found that the concept of an external entity was the most common depiction for patients describing the seizure experience, particularly in the sense of a battle with an external entity (Schwabe et al., 2007, 2008; Surmann, 2005). Grace did not initially describe a battle, but rather a hopeful bargain with God shortly after her

diagnosis. In her bargain with God, she promised to “straighten up” if her seizures would go away, likening her disciplined moral behaviour (i.e., no more drinking alcohol or staying up late) to a disciplined body. Both the perception of morality and culpability surface in Grace’s narrative, and this theme has been previously identified by Schneider (1988), though not in the physical descriptions that Grace uses to refer to the physical care of her body and posture. As Grace’s seizures continue to have a greater impact on her body and her daily function, we hear a description of a physical “fight” against her seizures and her physical self:

Ya, well, definitely when I was still having seizures there was a time when I really had to fight hard. I had to really invest a lot of energy in it. I... you know, I learned how I was going to manage physically with my seizures to manage my safety because they were so frequent in the morning. So... you know, you learn not to have a sharp knife in your hand! (Laughter). And uh... other things like that. You learn not to stand up in the shower, you know, not to have a bath and so... there were all those things that, ya, like I said I invested a lot of energy in that.

What struck me in Grace’s description of her seizures was her attempt to make sense of her epilepsy experiences based on the externalized control of her physical actions. It seems rare that Grace speaks as though she herself had a role to play in her seizure occurrence. Grace’s seizure descriptions parallel two of those identified by Schwabe and colleagues. The first involves the sense that an external entity is causing a change in the individual’s state (Schwabe et al., 2007; Surmann, 2005), which Grace refers to when describing seizures that involve a change in her degree of consciousness. The second seizure description was that of having one’s limbs moving of their own volition, which Grace refers to in reference to the physical “jerks” and “twitches” that she experiences while still conscious (Schwabe et al., 2007, 2008). Grace turns to

these externalized metaphors repeatedly as she shifts from the task of making sense of her seizures, to the question of how to behave in response to these occurrences.

8.6 Perceived Stigma: A Public Affair

While Grace describes a lack of familiarity with her less invisible or unconscious seizure experiences, her diagnosis and the reports of others begin to construct her reality. She explains that, given that she had no way to prevent her frequent loss of physical control, she had no choice but to acknowledge it when it occurred in public venues. In regards to others' knowledge of her epilepsy and these visible seizures, Grace reflects: *"There really wasn't much to control. It was out of my hands."* While she identifies herself as acknowledging her visible seizures, she nonetheless reflects on inhibited social behaviour in which she would not discuss her seizure occurrence unless others openly commented on her behaviour. Grace expresses her tendency not to address her seizures: *"People... didn't ask. They just didn't ask. And I didn't always tell them. It was just the way that I, that I was."* In a more dramatic example, Grace explained that she did not address her sometimes physical actions:

Ya, like there's one guy and he must have had a thing for me cause Fridays he'd be all shaved and aftershave and he'd sit next to me on Fridays in this one class and one day my arm just went, whack! (demonstrates throwing arm straight out to the side)... and hit him across the chest! I never said anything. (Laughter.) Neither did he!

In a review of patient knowledge of epilepsy, Baker (2002) found that many individuals chose to isolate themselves or limit communication regarding their misunderstood seizure experiences. This was found to increase the likelihood of psychosocial burden for new patients who were unfamiliar with epilepsy and therefore were less comfortable discussing seizure occurrence (Baker, 2002; Panter, 2004). Grace identifies many such instances at the beginning of

her illness, while she describes a large increase in comfort once she has greater control and understanding of her seizures, as has been identified in empirical studies (Jacoby et al., 2007).

8.6.1 Perceived stigma and culpability: “I didn’t do it.” A theme that has been previously identified and that was reiterated by this group of participants was a sense of perceived culpability for their epilepsy, particularly for seizures over which they had little to no control. Goffman (1963) was the first to introduce seizures conceptualized as “deviant behaviour,” and this concept has persisted and informed research regarding perceived stigma in individuals with epilepsy (Jacoby et al., 2005; Kiliñç & Campbell, 2009; Schneider & Conrad, 1981; Snape, 2015). I argue that the perception of culpability can be a necessary precursor to stigma, as individuals who do not perceive these actions as ones that should be within their control may not anticipate or perceive stigma (Jacoby et al., 2007). That is, despite the fact that participants themselves may not be aware of their own experience or, if aware, may perceive it to be externally controlled, individuals may still perceive that they have an obligation to take responsibility for and explain their behaviour (Jacoby et al., 2005). Grace describes multiple occasions on which all involved misunderstand the agency associated with epilepsy and seizures including the individual with epilepsy, as well as those observing the seizure. Given that individuals with epilepsy can have difficulty understanding their loss of physical control during a seizure, particularly in the early stages of the illness (Baker, 2002), it is not surprising that others might also have difficulty understanding the events taking place. In the following example, Grace speaks of her first time witnessing an epileptic seizure:

Grace: *I had a friend who had petit mal epilepsy as a child. And that was the only experience I had had with it before and/*

Me: */What did that mean to you?*

Grace: *It's funny cause I didn't really even know she had epilepsy. Uh... her name was Suzy. We'd say, "Suzy went blinky." Like, for a while we thought she was doing it on purpose and we'd tell her to stop. And she'd say, "I don't know what I did."*

Here, the misperception is that Suzy was acting of her own accord; she was believed to have control over her body and its actions. This presumed physical agency comes with the expectation that she should be able to change or stop her behaviour, despite the fact that she has no awareness let alone control over her own actions. It is worth noting that these are the actions of a 12-year old child, as witnessed by her peers, and therefore understanding may be limited based on life experience. Nonetheless, what does that teach the child in terms of her own agency over her own body? When and how, if at all, does this perception change among individuals, both those experiencing involuntary bodily functions as well as those witnessing them?

In an incident that can be said to parallel her first experience with epilepsy in childhood, Grace explains that she did not believe that epilepsy would impact how her peers perceived her until she was caught off guard when others did treat her differently. She describes an incident as a teenager, early in her epilepsy career, of a peer who witnessed her seizures and held her accountable, while her own confusion resulted from her lack of agency over her body's actions:

Grace: *It did lead to some confusion at times when I would see subtle changes in how people treated me. You know, like one of my friends for example was really annoyed because I always seemed to have a seizure when I was with her. And it's like, "I can't help it! It's not like I'm doing this to you on purpose!" You know, so it... ya, I just couldn't figure out like, "Well, why would you be annoyed with me?"*

Me: *Mm-hmm.*

Grace: *You know, "What did I do to you, really? Yes, I know I had a seizure... but I didn't do it."*

Grace's final statement in this passage powerfully illustrates confusion that individuals must grapple with when trying to communicate and comprehend the role of agency in the seizure experience. While Grace initially describes confusion regarding her seizures, her experience of a tonic clonic seizure and subsequent diagnosis of "epilepsy" enables her to label her behaviour for others, providing the biomedical label of "seizure." This empowers Grace to assert that she was not responsible for her physical behaviour; nonetheless, she still lacked an understanding of "who" or "what" external agent was responsible for her seizure occurrence (Schwabe, 2008). As such, her friend's accusation of this deviant behaviour remains unanswered. Further education, particularly at the point of patient diagnosis but also in regards to public awareness in general, might serve to address such misunderstandings.

In the past, social theorists have suggested that epileptic seizures may be perceived as "deviant behaviour" that may lead to the stigmatization (perceived or enacted) of individuals with epilepsy (Goffman, 1963; Jacoby, 1994; Kleinman, 1995). Particularly in the case of childhood seizures or seizures involving a lack of consciousness, I observed individuals as perceiving stigma in steps, in that they appear to be directly or indirectly held responsible for their seizure experience before they themselves are even aware of its occurrence, and only then perceive a sense of culpability for this "*externally caused experience*," leading to a perception of stigma. Medicine and scientific research has made early and continuous strides in identifying the neurological basis of epileptic seizures (Berg et al., 2010; Blume et al., 2001; Fisher et al., 2014; Temkin, 1971). Nonetheless, sociologists and psychologists continue to identify a large gap between the medical understanding of epileptic seizures and how these events are perceived by patients and the general population (Alcauskas & Charon, 2008; Angus-Leppan & Parsons, 2008; Nijhof, 1998). This discrepancy can be particularly difficult when individuals, like Suzy, are not recognized as having seizures given the lack of public awareness of diverse seizure typology

(Jacoby, Gorry, Gamble et al., 2004; Young, Derry, Hutchison et al., 2002). As such, both patients and the public may benefit from education regarding the accurate presentations of epilepsy.

8.7 Physical Control and the Lifecourse: “Drifting”

Given that a large part of her narrative focuses on her physical identity as a dancer, it is perhaps not surprising that Grace, more than any other participant, uses embodied descriptions (Scarfe, 2014). Her physical language is used both literally, to describe voluntary and involuntary movement of her body, as well as figuratively, to convey her psychosocial journey as it is impacted by epilepsy:

Umm, well ya, you know, as a seventeen year old, that’s when I started having seizures and, ahh... at the time I just was... kind of drifting along, I didn’t work very hard in school cause I didn’t really see a point, and I absolutely loved ballet so I worked very hard with my dancing, and... you know, I was just kind of enjoying things day to day and... so, you know, then the seizures started. And... you know so then a lot of things were taken away from me because, you know, I no longer had the control over my body that I could, you know, count on. Umm... I was really confused, like this was just really bizarre. What was this happening to me? Why couldn’t I make it stop?

For Grace, her early experiences of seizures and the related loss of control are conveyed with language that seems to focus on the body and the physical self. She begins her narrative and frequently returns to the theme of herself as “drifting.” Drifting has previously been conceptualized as a passive movement in which one may travel alongside the traditional or expected path of life, building on the traditional metaphor of “life as a journey” (Lakoff & Johnson, 1980; Schmitt, 2005). Grace’s use of “drifting” initially addresses her passive and

carefree movement through her academics, while her focus remains on a disciplined and controlled body in ballet. After she started experiencing seizures, she identifies a need to avoid “drifting,” stressing that epilepsy caused her to lose focus in life and caused her inability to control her body in ballet. The contexts in which Grace uses this term make it apparent that she perceived drifting as acceptable until she “*no longer had control over my own body,*” at which point she began to prioritize movement along the traditional life course that is controlled, directed, and in which one is actively engaged. This shift in focus at age 17, seemingly prompted by the experience of epilepsy, is the first in Grace’s embodied terminology that provides us insight into the role that the illness plays in her life course.

In the interview, Grace retrospectively describes how epilepsy was the obstacle that changed her life course in a positive way, from a passive “drifter” to a woman who must “focus [her] energies” to reclaim control over her body and life, and ultimately learn from her challenges. I suggest that Grace, more than any other participant, uses embodied terminology to script what could be read as a quest narrative of overcoming, and making positive gains, from her experience with epilepsy (Frank, 1995). Over several years of treatment adjustments, she considers herself as first directing her energy at gaining control over her epilepsy, then directing her energy towards the academic study of the physiology. She stresses that her parents would not allow her to “drift,” highlighting their role in the direction of her medical and academic journey.

Grace and her father, Alfred, both discussed the fact that it was not until he had witnessed his daughter’s seizures that he disclosed to her that he too had epilepsy. Alfred’s choice to remain silent in fact speaks volumes and modelled for Grace the tradition of keeping epilepsy hidden. Grace also described how her father modelled the ways in which she could overcome this challenge, including their joint attendance at an epilepsy support group. Despite minimal communication between this father and daughter regarding their shared illness, they both

overcame epilepsy and achieved successful careers by returning to a linear path despite the missteps caused by their seizures. Alfred's significant impact on his daughter's concept of coping with epilepsy can be illustrated in the way that she describes him as a "template" who demonstrated that one can "*be intelligent, successful... and have epilepsy,*" albeit primarily invisible in Alfred's life course.

Grace identifies epilepsy as a challenge to her independence at age 17 that set her five years back on the "straightforward" life course; she nonetheless prides herself on quickly learning to have everything "under control." She identifies many strategies that she used to gain this control by making her illness "tangible," that is, by making concrete and interpretable markers of seemingly nonsensical and often less visible body actions:

Then I started with my record keeping... I would just keep all these records, you know, I would try and keep a record of like, how many myoclonic jerks I had. Or... how many days did I have myoclonic jerks and absence seizures? And I'd be keeping track of my period, well, you know was it worse when I had my period or, ahh, no correlation at all? And, after a while, this just became a habit and I just, kept these records even though they didn't really serve any purpose. And... so I think that was part of my control thing though. To just, record it and compartmentalize it.

Here, Grace introduces us to one of the primary challenges faced by individuals for whom the invisibility of certain seizures is a double-edged sword. While acknowledging or addressing visible seizures makes them more tangible, it also makes them more public. Dissatisfied with the lack of explanations provided to her by the medical community regarding her symptoms and medication side effects, Grace tracks her seizure occurrence and attempts to identify possible seizure triggers and patterns in occurrence. Not only does this strategy provide Grace the opportunity to record her illness; as she states, she also has the opportunity to "compartmentalize

it” which allows her to intellectualize it, study it, and distance it from her own self (Jacoby et al., 2005). This strategy of distancing of her illness from her identity is key for Grace, as her primary focus is “independence” and “freedom” from her illness. These terms can be seen to imply release from the external control of epilepsy with return of control to Grace (Kirchglässer, 1990; Radley, 1993), which she experiences in a primarily physical, as opposed to psychological, realm:

Not having seizures made life more straight forward and I had more freedom. I could drive again. I could take dance lessons as I didn't have to worry about suddenly having a myoclonic jerk while executing a pirouette. I didn't have to worry about accidentally poking myself in the eye with a mascara wand. I became a nurse and specialized in critical care. I got married. We bought a house. The usual things. (Written narrative)

Grace's examples as proof of her freedom are physical actions, varying from basic muscle control to more complex examples of driving a car, as a powerful symbol of independence in the epilepsy community (Devinsky et al., 1995). Her return to dance is noteworthy in that she not only focuses on this central interest that was impacted by her early seizures, but she also emphasizes the lack of worry about loss of physical control. As we have explored in other narratives, worry about having a seizure, or worry about losing control, can be a more intrusive limitation than loss of control itself (Devinsky et al., 1995). Grace's list of examples suggests that the “usual things” appear to be unachievable without control of these more basic physical functions. This central role of basic physical control and activity makes it clear that Grace's achievement of freedom is one in which she is free from the experience, even the possibility, and thus the worry of a loss of physical control.

8.8 Enacted Stigma: A Consequence of Invisibility

It was interesting that Grace's depicted experience of enacted stigma occurred in an interaction at a peer-support group, and involved her lack of visible physical symptoms as the main focus of criticism. While Grace largely described the support and mentorship that she received from the local organization for epilepsy, the importance of a truly "shared experience" comes into question. Epilepsy is an illness that can present with diverse symptom presentation and can be considered transient in the sense that the illness can largely be invisible with windows of visibility when individuals are experiencing noticeable seizures, the visible manifestation of the illness in the brain (Jacoby, 2005; Stirling, 2010). Schneider and Conrad (1980) have made note of the difficulty that individuals with an invisible illness can face when choosing not to acknowledge their illness and to lead an invisible — and in theory stigma-free — life. While Grace is open about her condition, her seizures are no longer visible, and she is then challenged regarding her ability to share the epilepsy experience:

Grace: *The [President of the local organization for epilepsy] kinda in a way discriminated against me because I didn't know what it was like to have epilepsy.*

(Laughter)

Me: *Hmm. That's interesting.*

Grace: *I was like, "What do you mean?" And... and it wasn't until I told her, "No! I have epilepsy and I had uncontrolled seizures for 8 years." And I said, "I had to crawl on my hands and knees every morning to get ready in the morning." And she said, "Oh... Oh, I didn't realize." And I just thought, "You're nuts!" (Laughter)... ya, you know... ya, so that's a very peculiar thing because it was as though I didn't have any credibility because I didn't know what it was like.*

Grace not only feels the need to assert her credibility by stating that she has epilepsy, but specifically by recounting her history of uncontrolled physical seizures. In keeping with her focus on the physical, Grace specifically describes her daily physical struggles to manage while she was experiencing ongoing disruptions due to her seizures. Despite the role of the local organization for epilepsy as a source of support, it is noteworthy that this enacted stigma comes from a peer with epilepsy who challenges Grace's credibility for not demonstrating what was considered to be "epilepsy behaviour." Similar reports from the study of other illness support groups illustrate this narrative conformity, in which individuals are expected to endorse similar trajectories and conform to a prescribed narrative in order to have their experience validated by their peers (Holstein & Gubrium, 2007). Grace's narrative, which demonstrates multiple seizure types within one person's experience, seems helpful in gaining perspective into the diversity of possible interpretations and the danger of narrative conformity for those with epilepsy (Frank, 2010; Stirling, 2010).

8.9 A Second Diagnosis: "Here We Go Again"

In addressing the occurrence of a second chronic medical condition in later life, idiopathic cardiomyopathy, Grace reflects on the feeling of again losing physical control over a body she has learned to manage:

Me: You said, "Here we go again?"

Grace: Ya... ya... you know, once again, not having control again. Not having control over what my body was doing. I knew that something was wrong with my heart but not knowing what was wrong with my heart, not knowing what was going to happen to me and... so... ya.

With this loss of control, Grace's emphasis on the need for respect from her physicians is even stronger, with her greatest focus on the need to be listened to. She again highlights the theme of listening to her and respecting her as a partner in her own treatment. Here we also observe her reflection from the perspective of a cardiac nurse, where she expresses a need for clear communication on both sides of the patient-practitioner partnership in order to establish the best treatment. She describes repeated interactions where physicians attributed her cardiomyopathy symptoms to her epilepsy:

Ya and... it made me really angry. Because... for one thing, I'm a person. You know, I know what I experienced. For another thing, I also am rather knowledgeable in that area and... I know, kind of the history, you know, what was going on at that time and... and, it's like, "No. You're telling me a bunch of bullshit. You're not listening." And, um... so ya, then as a nurse there was that, "You're not listening."

She then describes thoughts from her perspective as a nurse:

So ya, you know, you, as a nurse you have to learn to be very good at listening and not putting words in a person's mouth so, ya, as someone who then wound up, you know, on the other side, um... to once again not be listened to... it's maddening.

In part, it feels as though we are listening to Grace at a younger age in her attempts to receive an accurate diagnosis and treatment for her epilepsy. She expresses significant frustration that despite having developed seizure control, an understanding of epilepsy, and medical expertise through her education, she is still not listened to in the same way that she felt unheard in her early years with epilepsy. Her frustration appeared particularly strong when physicians first attribute her heart condition to her epilepsy. She reflects on how this has impacted her occupation, explaining that she has learned that one can “*undermine a lot by not listening*” and that she tries on all occasions to be a good listener to her patients. A final note that Grace

informed me of, highlighting its strong role in her life and her priorities, is that despite a return to dance, she had been forced to quit with the occurrence of this new illness.

8.10 Conclusion: Hearing the Body

Nearing the end of my interview with Grace, I asked her if she had any specific words or metaphors that she would use to describe epilepsy. While she had provided me with numerous rich metaphors, this was an opportunity for me to compare what I experienced as the most significant language and narrative segments with what Grace saw as central, as well as most representative of epilepsy. Her response strongly informed the analysis of her narrative, as well as reinforcing the significance of her earliest experiences with epilepsy, her loss of physical control in the context of dancing:

Grace: I can't really, think of anything else to describe it other than that loss of control.

You know, in my work sometimes I just, I see these... images, you know, of people and their families and they just... strike me and I wish that I could portray them somehow as an artist and so then when I was still dancing, you know, sometimes it would come out through that, you know, that... I, I, I would just be so grateful that I had what I had. You know-

Me: /mm-hmm/

Grace: /that I had that freedom to, to dance and to move and to have the control over my body and I, um... because there's people who don't have it. I guess also because I know what it's like to not have it sometimes. So ya, I think maybe in some ways it comes out in non-verbal ways.

While Grace's narrative ended with the encounter of a new illness, the focus seems to remain the same throughout: a need for control dominated by her desire to function in her

physical world. Not only does she repeatedly default to physical terminology in the description of her illnesses and her daily activities, but she uses this language to trace the path that she travels, the obstacles she encounters, and the battles that she must win in order to gain control over a body that is rogue. Grace's initial level of secrecy and perceived stigma regarding her symptoms has become a more public affair by the time she and I discuss her experiences, to the extent that she has even confronted peers with epilepsy. She acknowledges that she is a secretive person, but that her experience of empowerment through education, peer support, and respect from those physicians that listened has enabled her to move on to the "usual things" in life, be they physical or professional challenges. With a recent loss of control to another physical illness, Grace maintains a focus on the physical, but enters the process of diagnosis and treatment with a learned level of assertiveness. Grace's closing line in her description of how to communicate around epilepsy reminded me that illness representations are not only a matter of language, but of physical and artistic representations as well.

Grace's narrative highlights the multifaceted experience and communication of representations surrounding epilepsy. While all participants certainly described the physical experiences associated with epilepsy, arguably the most prominent feature of epilepsy from a public viewpoint, Grace focused on the physical in all elements of her narrative. It is fitting then that her narrative brings us to a final section of comparisons across participants, one in which the diversity of epilepsy representations can be considered for the similarities and differences that I perceived across the narratives.

CHAPTER NINE

Shared Conceptualizations of Epilepsy and Control

As identified in the introductory chapters and revisited throughout the individual narratives, a primary finding was that many of the participants seemed to use metaphors and conceptualizations as tools to communicate experiences of control surrounding their epilepsy experiences. As such, I will next return to the literature to provide a brief overview and reminder of the relationship between epilepsy and control, particularly as it relates to my findings. Each narrative will then be considered individually, highlighting those conceptualizations that appear to reflect participants' perceived control in relation to epilepsy. For each of the narratives and conceptualizations revisited, I will consider how other participants may or may not utilize similar metaphors or conceptualizations in their epilepsy experiences. I will then highlight those metaphor targets and themes that appeared to play key roles across participants. This will lead me to provide insights and recommendations for the consideration of language use in clinical and everyday interactions.

9.1 Returning to the Literature

Individuals who receive an epilepsy diagnosis have all experienced a loss of physical and/or cognitive control at least once, with the occurrence of their first seizure (Fisher, 2015; Kwan et al., 2010). All individuals diagnosed with epilepsy may have a tendency to base their narratives on diverse conceptualizations, medical descriptions, and societal interactions that reinforce this initial or recurrent lack of control (Kwan et al., 2010; Téllez-Zenteno et al., 2014). This was a finding based on my analysis of the narratives and, once noted, I returned to reconsider this trend in the context of my initial review of the literature (e.g., Kilinc & Campbell, 2009; Nijhof, 1998; Scambler, 1994; Schneider & Conrad, 1983), as well as newer publications

(e.g., Rugg-Gunn & Sander, 2012; Tang et al., 2014; Velissaris et al., 2012). While the findings I reviewed began with early sociological studies regarding epilepsy and loss of control, a majority also included research and autobiographies that were published in the time since I first carried out my interviews and much of my analysis. What I find interesting and novel about the results of my analysis are the diverse approaches taken by the narrators to frame their experiences around the perceived role of control, both lost and reclaimed, in different domains of identity (Charon, 2006). Each participant appeared to begin by expressing her or his first seizure experience as a loss of control, labelled as such literally and/or metaphorically. Participants then appeared to engage in attempts to reclaim control, albeit through different approaches and conceptualizations. These different conceptualizations and the domains of identity impacted will be compared across participants after a brief review of the research surrounding the relationship between epilepsy and control.

9.1.1 Epilepsy and control. Control is a topic that frequently arises in research of people with epilepsy, though the ways it is identified and addressed has varied with time and research approaches. Without taking the time to consider epilepsy in the different fields of research and practice, one may not realize that this term arises with similar frequency, albeit with different definitions and to serve different purposes. In the biomedical forum, academic papers and physicians use control primarily as terminology applied to seizures (i.e., “well-controlled”) and seizure management (i.e., treatments provide “full control”). From a biomedical perspective, the most clinically relevant treatments are those that provide good “seizure control,” or “lifelong seizure freedom without adverse effects” (Kwan, Arzimanoglou, Berg, et al., 2010, p. 1071). The epilepsy population who lacks seizure control based on biomedical definitions is estimated to range between 28.4 to 38 percent (Téllez-Zenteno, Hernández-Ronquillo, Buckley, et al., 2014).

A biomedical description from the online forum WebMd states, “If your doctor says you have refractory epilepsy, it means that medicine isn't bringing your seizures under control. You might hear the condition called by some other names, such as uncontrolled, intractable, or drug-resistant epilepsy” (Lava, 2017). This terminology is often shared in patient-physician interactions, and is also applied to the patient experiencing the seizures (i.e., the patient has been able to achieve control).

In the moments following seizure activity, people with epilepsy often seek to regain control of their own body after consciousness and physical movement may have been compromised (Jacoby, Gamble, Doughty, et al., 2007; Téllez-Zenteno, Dhar, Hernandez-Ronquillo, & Wiebe, 2007). DeVillis and colleagues (1980) were among the first to address perceived loss of control in epilepsy patient experiences, focusing on the relationship between individuals' perceived seizure control and the impact that this had on their psychosocial well-being. Perceived control, and more specifically control of one's epilepsy identity, prevailed as a primary focus for researchers following Schneider and Conrad's (1983) seminal work (e.g., Hermann & Wyler, 1989; Kirchglasser, 1990; Scambler, 1989). Ongoing psychosocial research continues to point to identity control as a struggle for individuals with epilepsy (Jacoby, 2005; Kilinc & Campbell, 2009), sometimes seeping into relationship roles (i.e., partner or parent; Brosh, 2011), life roles (i.e., academic, athletic, or work performance; Scarfe, 2014), and ultimately impacting one's core perceptions of self (i.e., trust, questions of identity, internalized stigma; Elliot & Richardson, 2014; Snape, 2015; Velissaris et al., 2007, 2012).

Brosh (2011) highlighted the benefit of psychotherapy for individuals with inadequate seizure control, as well as those struggling with identity control related to larger societal and legislative epilepsy discourses. Sociologists and psychologists have documented the way in

which the struggle for control presents with individuals striving to control or reclaim their identities when faced with the social consequences of a public seizure or an epilepsy diagnosis (Faircloth, 1998; Schneider & Conrad, 1983; Scambler, 1994; Snape, 2015). Many individuals living with chronic illness develop coping strategies that focus on regaining control through self-management in the medical, lifestyle, and social arenas (Kemp, Morley, & Anderson, 1999). Neurologists and clinical psychologists have addressed the psychosocial burden of epilepsy through psychoeducation regarding epilepsy and seizure management, so as to increase perceived self-control (Michaelis et al., 2012; Tang et al., 2014). Patient interaction style and language, including metaphor, have been identified as a specific approach for physicians looking to assess whether individuals with epilepsy are achieving positive coping strategies and a healthy sense of control (Monzoni & Reuber, 2009). Control has received different definitions throughout epilepsy's history in cultural, academic, and clinical settings, and it continues to play a central role in the lives of those living with epilepsy.

9.1.2 Metaphors and control. Studies of control in biomedicine, sociology, and psychology are by no means mutually exclusive. That is, control has been approached from biomedical research with consideration of improving diagnosis and patient care, including psychosocial consequences and treatment. In linguistic and diagnostic evaluation of individuals who had experienced seizures, the primary finding was that individuals with epileptic seizures tend to use metaphors that focus on a lack of control (Schwabe et al., 2009; Plug et al., 2009, 2010). More specifically, those experiencing epileptic seizures ascribed loss of control to an external source (Plug et al., 2009), describing seizures as an externalized “other” that acted upon them or an external “place” that they had no control in entering or exiting. Researchers and clinicians have started to recognize the therapeutic benefits of increasing perceived control in epilepsy patients (Michaelis et al., 2012; Sperling, Schilling, Glosser, et al., 2008; Stone, Binzer,

& Sharpe, 2004), and I believe that there is further potential in utilizing the control-related metaphors identified by Plug (2009) and colleagues to improve treatment practices (Reuber & Plug, 2003). More specifically, providing patients the opportunity to express their concept of epilepsy through their own narrative could lead to improved quality of care for people with epilepsy. For example, a study in which persons living with AIDS were asked to provide imagery of their illness, cognitive conceptualizations were identified as a helpful indicator of the individuals' illness experiences, coping behaviours, and necessary psychosocial supports (Anderson & Spencer, 2002). Similar to the study by Rätty (2009), descriptions that focused solely on physical symptoms (e.g., "bodily destruction") were contrasted against those with greater psychosocial implications (e.g., "devouring life" and "black cloud of death"). The findings provided a novel strategy for patient-caregiver communication in addressing physical and psychosocial needs associated with illness (Anderson & Spencer, 2002).

9.1.3 Control in the current study. From participant narratives in the current study, the primary focus that I observed was initially attempts to regain control after the first seizure(s), which often extended to attempts to regain control in other life domains. Below, I will briefly revisit each of the individual narratives with the purpose of highlighting those metaphors and conceptualizations that appeared to play a central role in individual narratives. I consider if and how these metaphors surfaced for other participants, as well as the prevalence of these metaphors in other research or clinical literature. Finally, I consider the relationship between these varied metaphors and participants' conceptualizations of perceived control. This serves as a summary of findings, with reflections on how attending to metaphor can benefit those involved in communication surrounding epilepsy experiences, from public education to patient-practitioner dialogues.

9.2 Analytic outcomes: Individual voices, common threads

I will now review the metaphors, based on common metaphors and metaphor targets that were present across my participants' narratives. As stated, the most prominent finding in qualitative studies has been the element of loss of control in epilepsy, albeit in different aspects of the epilepsy experience (e.g., Schneider & Conrad, 1981, 1983; Snape, 2015). While the participants outlined similar stages in their epilepsy narrative trajectories (e.g., first seizure, diagnosis, social identities, treatment, etc.), the narrative identities that they presented differed in terms of what particular element was their main target for controlling their epilepsy, and in many ways their identities as individuals with epilepsy. Each of the participants emphasized a perceived loss of control following the first seizure, whether stated explicitly within their seizure narrative or as described early in our narrative encounters. Because this theme appeared to cut across all narratives, my interest was then directed to what metaphors were used to convey this loss of control, and furthermore, how control was then characterized throughout the narratives. I further questioned what domains — and communicated through which words — had become the focus for an attempt to regain this perceived control. Given that my research focused on metaphor use, as well as the origins and purpose of the terminology used, I focused on those terms that played the most central role in patients' narratives, with particular attention to those used in reference to control. I structured my case studies to present each individual's narrative as a whole, each providing focus on the theme or group of metaphors that seemed most pervasive in each individual's narrative of epilepsy experiences. Because each participant spoke of perceived loss of control, I included these descriptions in the chapters as a necessary and often central piece of the story. Next, I will review metaphors contributed by each participant, consider how these terms may or may not relate to the narratives of other participants, and then consider the relationship between these terms and perceived control in epilepsy experiences.

9.3 The “Witness”: Metaphors of Identity

Hannah emphasized shifts between seemingly different identities and roles— such as witness-witnessed and victim-healer — in her experiences of seizures and epilepsy. It was her use of the term “witness” that appeared to reappear in other narratives in this study, as well as in past epilepsy narratives and epilepsy narrative research. As such, this is the metaphor that I explore further. The role of “witness” in the case of illness narratives can be used in reference to researchers, clinicians, family members, or even the patients themselves, and this term can hold multiple meanings.

Bury (2001) highlights the moral witness role as a common portrayal in “moral narratives” in which the ill person is cast as a victim of circumstance, but that their guilt (of being ill) is nonetheless perceived as the patient’s fault. Kleinman (1988) also made a strong case for a need to bear witness to the suffering of those with living with illness by listening to their narratives, so as to acknowledge the person as a whole and gain a greater understanding of their experience. While multiple researchers reflect on the need to bear moral witness to stories of illness from the psychosocial perspective (Kleinman, 1988; Frank, 1995, 2010), the term “witness” also plays a central role in the case of seizure and epilepsy diagnosis in the biomedical domain (Rugg-Gunn & Sander, 2012; Smith, Defalla & Chadwick, 1999). Within the biomedical community, it has repeatedly been asserted that an epilepsy diagnosis can only be made when there is an observer, an “objective” witness, who can accurately describe the seizure occurrence (Rugg-Gunn & Sander, 2012):

The diagnosis of epilepsy is clinical— that is, it is made on the basis of a description of the seizure by both a patient and a witness. It is mandatory to try to obtain a witness description, which is often more informative than the person’s account of the event, which may be confounded by loss of awareness, confusion, and amnesia (p. 4576).

A majority of epilepsy narratives, including every one that I collected, involve participant reports of others who have “witnessed” their seizures and what their reactions were (e.g., Brosh, 2011; Schneider & Conrad, 1983; Snape, 2015). Each individual that I spoke to described their first “witnessed” seizure, which was not necessarily their first seizure but was often the precipitant to seeking medical care and diagnosis. While the term “witness” arose in each narrative, the role that it played varied. Participants indicated different sources when narrating their first witnessed seizure narrative; some participants presented the narrative as solely informed by their own experience of the seizure, others identified this narrative as a report from outside observers (often labelled as witnesses), and still others acknowledged this as an integrated narrative informed by their recollections of the seizure and reports from observers. For the majority, this concept of a witness appeared to hold both biomedical and psychosocial meanings and was introduced, at least initially, as the role of the individual who witnessed their first seizure.

Hannah negotiated this role in such a way that she presented the transition from the ill person being “witnessed” to a “witness” of others’ seizures, first avoiding the role of witnessing others’ seizures, then retrospectively willing and wanting to engage in this role. While Bury (2001) emphasizes that the role of a witness need not be of a spiritual nature, there is at least a moral if not spiritual tone about Hannah’s conceptualization, as she shifts from a “victim” being witnessed, to a “healer” who is wanting to witness others’ experiences and provide support. This moral transition is also consistent with individuals who locate themselves in Frank’s (1997) remission society, identifying as an individual who has become “successfully ill.” For Hannah, she appears to define this success by her ability to accept and to an extent manage her seizures, and further to serve as a witness to those experiencing seizures. Similar to Hannah, Clark spent a majority of his seizure descriptions on the witness side of the narrative, describing how he had

overcome his seizures with a focus instead on being a supportive observer and an advocate for others experiencing seizures. Clark further appeared to take it upon himself to educate medical students regarding seizure typology by acting out a fake seizure at a public lecture, a process in which he not only seemed to take ownership of the seizure experience but in effect created a room full of witnesses.

There appeared to be some disparity as to whether or not participants wanted to be witnessed. Clark expressed relief after a medical resident witnessed him in the biomedical sense, observing his seizure and providing him a correct diagnosis, after repeated misdiagnoses of “anxiety attacks” based on Clark’s own subjective descriptions of his seizures. Similarly, Cam described himself as *“lucky to have had a nurse witness [his] first seizure,”* as it provided him with an immediate explanation and label for his condition before he himself was reportedly aware of his seizures. His seizure narrative was presented as two sets of facts: his subjective experience of no seizure at all, and the objective observations of the nurse in what would traditionally be seen as the role of the biomedical witness. In contrast, Grace and Hannah both reported seizure experiences that they initially chose to hide from others, until uncontrollable and physically visible seizures were witnessed by their parents and led to their diagnoses. Grace described a similar conceptualization presented by both women, in that they chose not to acknowledge or disclose their seizures because *“you know, of course if I say something to my parents, then something’s wrong.”* While this implies anxiety at the unknown and a potential for Bury’s (2001) question of moral witnesses surrounding an abnormal experience, both women expressed a certain degree of relief when their seizures were witnessed and acknowledged by others. As illustrated in Hannah’s narrative, she maintained control of the seizure story by shifting from the role of “witness” to “witnessed” throughout her narrative in order to create a coherent story of how a seizure occurs. This move between different roles may be an effort to *“fill in the gaps”* as

reported by Grace and as previously identified in epilepsy patient narratives (Schwabe et al., 2008), so as to create a coherent timeline and to be informed in the moments when one is not consciously present. It also provides, however, the opportunity to retain control of the plotline as Hannah and Clark both emphasize in their storytelling.

Rose's experience and descriptions were distinctly different as she herself had no awareness of her seizures until after they had occurred and she regained consciousness. She expressed that those who had witnessed her seizures were not interested in discussing what they saw. Her description of her first seizure involved her own confusion as peers stared at her without explanation, an instructor sent her to the school nurse without direct explanation, and she was reportedly forced to self-diagnose by looking in the mirror and attempting to make sense of her post-seizure injuries and appearance. This likely set the tone for the degree of privacy and perceived level of stigma she appeared to hold surrounding her seizures, reinforced by her family's insistence not to discuss her epilepsy (Elliot et al., 2005; Jacoby & Austin, 2007). While participants provided diverse conceptualizations of the witness role(s) perceived, each narrative appeared to attribute a certain degree of power and control to the witness(es) presented. Let us now examine this relationship between witness roles and control further.

9.3.1 Witness roles and control. As noted, the "witness" perspective described has been scripted within the domain of morality (Bury, 2001), as well as within the domain of biomedicine (Smith et al., 1999). Schneider and Conrad describe the "witness" concept as used in epilepsy (1983, p. 109) and emphasize the role that such a conceptualization can play at disempowering those with epilepsy. Much akin to what the current participants described, these researchers identified the way in which attention can be turned away from inner conscious and physical experience of loss of control during a seizure, to the outer social experience, intensifying the perceived loss of control as the experience becomes socially constructed by those witnessing the

seizure (Schneider & Conrad, 1983; West, 1979). For the observer, as well as those experiencing a first time seizure or the “naïve witness,” control is primarily perceived in the context of physical loss of control during a seizure. Such a loss of control could be characterized as the individual with epilepsy “falling victim” to an illness that has overtaken his or her body (Temkin, 1994). For patients who are processing their experience, it may additionally be a social and emotional loss of control in that they may feel they have lost their established sense of identity. As such, individuals may still perceive themselves as betrayed by their body or by an illness, but this time the central focus may be the social and emotional repercussions of victimization (Jacoby & Austin, 2007; West, 1979). Rather than a sense of physical struggle that is quickly lost, the individual may experience a more prolonged emotional struggle against the perceived perpetrator, a metaphor indicated in Plug and colleagues’ research (2009) and reinforced in the collected narratives. The “witness” is one example of a term that appears to be used with regular frequency in biomedical forums; a clear definition may help to ensure that the individual who has experienced the seizure understands the clinician’s interest in or use of this term. From a clinical perspective, the use of the term “witness” should be carefully observed and clarified if presented by an individual describing her or his seizure experience(s), and used with caution and awareness of its multilayered meanings and interpretations.

9.4 “Mechanics” Versus “Saviours”: Metaphors of the Mechanical-Spiritual Divide

Clark communicates his narrative with two main metaphors, the first being the mechanical language that he uses primarily in relation to his biomedical labels and interactions, as well as in his descriptions of epilepsy for educational purposes. The second metaphor is the spiritual language that he uses throughout narration of his epilepsy story beginning with the “epiphany” that led to his diagnosis. For Clark, rather than reject the epilepsy story, he appears to

embrace it and become a champion for the cause, creating the identity of Captain Epilepsy. Clark demonstrates an interesting but seemingly complimentary divide in his search for control, relying on mechanical terminology (e.g., the body as a machine, fixing a “broken brain”) mainly when referring to medical conversations, but ultimately providing a more comprehensive and coherent identity in the role of a preacher when medical treatment does not address his illness in its entirety.

Cam also focused on more mechanical descriptions; in connection with his time-based and workplace-focused changes in identity, he described his seizures as “glitches” in the system that were unnoticeable given his consistent performance before and after a seizure. He characterized a reliable, systematic function of his body and self that continued until his seizures became disruptive. Similar to Clark, it was at this point that Cam’s reliance on medical and mechanical labels began to break down, and he began to rely more heavily on his own labels and terminology related to his maintenance of Consistent Cam, of self, rather than rely on medical definitions. Cam described frustration in his interactions with his physician, where he perceived conflicting priorities; his physician wanting to increase medication and obtain “full seizure control,” while Cam argued a desire to maintain his quality of life, particularly his social relationships and identity, emphasizing an illness conceptualization. Both men returned to mechanical descriptions of their surgeries and medical labels associated with their surgical outcomes, suggesting perhaps that the conceptualization of “body as machine” became valuable when the “broken” pieces were able to be repaired.

9.4.1 Mechanical and biomedical metaphors and control. At one point or another in their narratives, all participants relied on biomedical terminology to convey experience. For many, they first presented a tentative diagnostic label of which they were unsure of the meaning. For example, *“I had a label of epilepsy, whatever that means”* (Grace, Oral narrative). Later on,

particularly as individuals sought a greater personal role in their treatment, they used terminology that reflected time spent researching and educating themselves about epilepsy, illustrating their mastery of biomedical terminology and indicating an attempt to educate and empower themselves through a greater understanding of the language with which they were being presented (Kirmayer, 1993; Kilinc & Campbell, 2009). Kirmayer (2000) emphasizes that this process is common in a culture that values rationality and control, and that education in biomedical terminology leads to feelings of self-efficacy and control. Indeed, Grace, Hannah, Rose, and Cam all identified a time at which they challenged their physician's prescribed treatment after years of living with epilepsy. Grace and Hannah reported managing their own "therapeutic levels" in blood tests, to ensure they were taking the lowest necessary dose of medication. Cam spoke of "titrating down" and "weaning [himself] off" of medication that he experienced to be ineffective in his treatment.

In an instance similar to Clark's illustration of the power of the physician's terminology, Grace reflected on her first neurologist and a lecture regarding the "electricity" of the brain, followed immediately by descriptions of being "catapulted" and as though "hit by lightning" while undergoing treatment with the same physician, seemingly adopting his metaphors of electricity (Kirchglasser, 1990). She then seeks out alternate care, and establishes a patient-physician relationship in which she feels listened to, highlighting the friend that she had in her neurologist, someone with whom she was on "equal footing." This again parallels Clark's relationship with his neurologist, whom he describes as a friend and his saviour. The frequent uses of mechanical terminology, often introduced by interactions with the biomedical field, highlights the role that education can play in helping individuals to understand the labels being placed on their experiences, as well as in enabling them to gain an increased sense of ownership

and control in the management of their illness. State Conrad and Baker (2010), “medical discourse can influence people’s behaviors, impact their subjective experiences of embodiment, shape their identities, and legitimate medical interventions” (p. 69). As such, effort must be made to ensure that language has been clearly understood and is being used by all parties with the same intention.

9.4.2 Spiritual metaphors and control. A majority of recently published epilepsy autobiographies feature individuals who retrospectively recall how they conquered or gained control of their epilepsy through successful surgery. Both Clark and Cam presented themselves as having achieved new and exceptional identities, emphasizing the accomplishment they had made in gaining seizure control through surgery. Nonetheless, these two individuals spoke of ongoing struggles to control additional seizures, adapt to surgical outcomes, and to make sense of the epilepsy experience as a whole. Cam introduced a new identity for himself entirely, distancing himself from the epilepsy label and attempting to control his experiences through new vocabulary. Clark’s surgical recovery involved “trading in” control of his seizures for control of his mood; additionally, rather than abandon the epilepsy label he has claimed it as his life purpose as a “preacher” and Captain Epilepsy with the goal of educating others regarding epilepsy.

Though not within the spiritual realm per se, Cam spoke fondly of the supportive relationships that he has established amongst the epilepsy community. While Hannah makes reference to the spiritual experiences of epilepsy, she identifies this as something experienced in her soul and not something that she holds as a social identity in the same way as Clark. While Hannah and Clark both described elements of spirituality, their narratives did not contain the same elements of religious ties as did some of the other narratives that I encountered, such as published narratives that cited demonic possession or biblical passages (e.g., Curry, 2003;

Kissing, 2006), nor anthropological accounts that highlighted communal beliefs about spiritual curses upon an individual or family (e.g., Good & Good, 1994; Kleinman, 1995). Spirituality has a long tradition of being connected to epilepsy and epilepsy personalities (e.g., Andermann, 2000; Bear & Fedio, 1977; Temkin, 1994), but for the participants I observed it appeared to play a role more so in identifying their social identities as a priority, rather than conceptualizations tying seizures to religious beliefs. While earlier epilepsy research, narratives, and cultural conceptualizations remained focused on the spiritual element of the once “sacred disease,” it is worth considering the evolution of this characterization and how its role has shifted in current day conceptualizations coming from general public discourse as well as those with epilepsy.

9.5 “Before and After”: Metaphors of Time

Cam’s narrative directed my attention to the importance of time, particularly in individuals considering their epilepsy and its course retrospectively. Time played a central role in Cam’s narrative, enabling him to utilize both diagnostic labels and personally-derived labels as time markers to indicate the role that epilepsy played in his life at each stage of the illness, including the transitions that it prompted (Charmaz, 1991). Cam’s descriptions of time varied, as he focused on the consistent self he was able to present before and after his seizures. This consistency contrasted with the inconsistent nature of epilepsy. Cam utilized labels of his own creation to characterize the stages of himself and his illness, as well as biomedical labels that were consistent with his perception of events. In accordance with a finding from Schwabe and colleagues (2008), Cam described his seizures as a “gap” in time and he compensated by illustrating his ability to detail the events “before” and “after” his reported “blip in time.”

Other participants characterized time in different ways, though many maintained the chronological trajectory prompted by early markers that determined how time would proceed in their illness narrative. Some participants placed their epilepsy in the past with diagnosis and first

seizures as the factors that were most disruptive and largely overcome, while others placed epilepsy in the present with ongoing complications or struggles to manage their illness. Hannah's story seemed to be an attempt to portray an "illness-as-normality" narrative (Frank, 2010), in that she characterizes both the predictable "ingrained" elements such as daily medication, as well the unpredictable resurfacing of symptoms as something "cyclical," perhaps attempting to impose a sense of predictability or at least acceptance. Grace could also be seen as portraying an "illness-as-normality" narrative in that she describes her medications as a daily routine that is otherwise minimally disturbed by symptoms. While Rose too reflected on earlier life realities of stability and seizure control, the majority of her narrative reveals a chaos narrative in which she is searching for labels, time markers, and indicators of what is to come given her perceived loss of control and lack of possible treatments to control her seizures (Frank, 1995). Rose reflects on her past and current struggles with epilepsy and portrays herself in decline. She repeatedly questions the consequences of aging with epilepsy, and reflects on the loss of power and mortality that she faces as her health continues to decline.

Cam's narrative is quite different from other epilepsy narratives, although the increased number of published portrayals of epilepsy in autobiographies would portray his story as the norm. That is, Cam describes epilepsy as a "curable illness" that indicates a temporal element of being cured and having epilepsy not as a chronic illness, but as an illness of the past. Cam describes epilepsy as a "reference point" and explains that prior to the surgery, he had epilepsy but that the surgical removal of his tumour also removed the label of "Epilepsy" from his identity. Thus, he now refers to epilepsy as a part of his past. He discusses an ongoing possibility of epileptic seizures, as well as the occurrence of what he identifies as non-epileptic seizures as diagnosed by his current epileptologist.

Clark also presents his epilepsy as something that he has overcome due to surgery; in contrast to Cam he is unwilling to “leave it behind.” In discussion of the change in his role since his surgery, he explains that he has become aware of the need for advocacy for those with epilepsy and will always be prepared to support and educate those who may need him as Captain Epilepsy. In this light, Clark may be seen as portraying a quest narrative, in which he may have regained his health and successful control of his seizures through surgery, but he has also been through a spiritual journey in which his identity has been significantly transformed (Frank, 1995). Having recognized that each individual appeared to have a different relationship with time, let us consider how this factored in to their conceptualization of control surrounding their epilepsy.

9.5.1 Time, labels, and control. Labels carry with them significant power and control, including control of one’s conceptualization of self, illness, and personal history. Despite the fact that I did not directly inquire about it, every participant shared timelines that recounted seizures, social encounters surrounding their epilepsy, and their diagnostic trajectories. As has been discussed, diagnostic labels can carry with them a certain degree of comfort when an illness becomes medicalized; however, this medicalization can also result in a perceived loss of control over the illness experience and illness identity (Conrad, 1992; MacLoed & Austin, 2003). Nonetheless, labels are important — for some these are the labels they have been given, while others appear to identify labels that they created or claimed — as these appeared to play a large role in the ongoing effort to recount and reconstruct the illness story. As Charmaz (1991, 2000) has reflected, illness-related labels can serve as time markers and turning points for individuals who are constantly re-constructing and attempting to make meaning of their illness experience. In regards to this attempt to make sense of the minimal control over time, Charon (2006) emphasizes that it is through narrative thought, “that humans are able to come to at least provisional accord with the relentless and merciless passage of time” (p.42). The participants

with whom I explored a snapshot in time illustrated the shared struggle to control time through memories, labels, and time markers, which can help increase the sense of control over an illness with an uncertain temporal progression.

9.6 The “Nest”: Metaphors of Social Boundaries

The most salient metaphors that I perceived with Rose were based on her apparent focus around social control throughout her narratives. I was fascinated by Rose’s narration of social boundaries, defining who and what was permitted in her safe “nest” in which she could safely reside, as well as those social interactions that caused her “nest to be shaken.” Rose’s designation of these boundaries appeared to be a product of her early experiences with seizures, family and peer interactions surrounding epilepsy, and seemed to gradually evolve into ownership of her role in interactions with her epilepsy, her physicians, and her community. Social control and related individual trajectories in epilepsy have been heavily researched by sociologists and medical anthropologists, and I suggest that the metaphors that I have observed, seemingly used by participants in efforts to construct social boundaries and establish social control, is of benefit in extending these research findings.

Schneider and Conrad (1980) presented “information management” as a strategy in which individuals strategically manage what illness-related details they disclose in order to minimize any negative impact that epilepsy may have on their public identity. While Rose and other participants identified this strategy as a means of controlling seizure-specific information, the management of social boundaries seemed to extend further in shaping their preferred identities. For example, most participants reflected on the impact of epilepsy on their role in the family, with Rose and Clark both choosing to move away from their families, reportedly to avoid burdening their family by making them live with epilepsy in their lives. Hannah demonstrated a

renegotiation of her epilepsy identity when she became a mother, attempting to acknowledge her own health needs to best fulfill her role as a mother, but ultimately becoming more critical of herself and seeming to be less open about who she shared her epilepsy identity with. For Grace and Cam, the boundaries drawn seemed less severe with unspoken agreements to speak minimally of epilepsy in their family so as to contain its role in family interactions. Grace interestingly spoke of her husband as a “blank slate” who knew nothing of epilepsy before meeting her; she spoke with pride and seeming satisfaction that she was the one to educate him, in a sense create her own boundary around what epilepsy was and the role that it would play in their lives.

9.6.1 Social boundaries and control. As has been established by research into seizures as a model of uncontrollable “social deviance” (Schneider & Conrad, 1983), individuals and those around them have sought explanations and attempts to control seizures, conceptualized as physical misbehaviour. Every participant provided their perceptions of epilepsy prior to diagnosis, and many provided perceptions that they encountered when disclosing their diagnosis to others. Hannah reflected on the stigma that she was aware of, even though she was unsure where she had first encountered it:

So even though I hadn't known anybody in my life who'd had epilepsy I think the social consciousness or the understanding that people who do, those people who do have epilepsy, you know, those people out there... I had some base knowledge that, from some sort of collective consciousness that they were other, they were, you know it was gross to watch, it was freaky, you know, just to see someone convulsing on the floor so it's not like a pretty scene, and that, just the whole thing about being... I knew a little bit about the history, about being lepers, being put on colonies because they weren't understood.

These participants all introduced those with epilepsy as necessarily distanced from the general population without epilepsy, reinforcing boundaries as an accepted and expected norm. Despite the fact that the focus of our conversations and writing was the very experience of their epilepsy, participants frequently provided externalizing labels for the group of “others” with epilepsy. Even if they socialized with others who had epilepsy or identified with the epilepsy label, all were keen to emphasize that they were more than their epilepsy and, as Rose stressed, they were not “epileptic.” Rose seemed to take this to the extreme, with denouncing the idea of epilepsy as being “tattooed,” paralleling Kilinc and Campbell’s (2009) identification of those who wanted to avoid epilepsy and not “wear it as a label.” All participants’ identities appeared as a mutual effort between their own self-concepts and their attempts to manage boundaries around the concepts of others, including who (e.g., family, friends, health care practitioners, the public) was permitted to participate in the lives of these selves; that is, who was allowed in and who or what might be kept out. While Rose appeared most focused on negotiation of “social boundaries,” all participants appeared to use unique metaphors for their specific negotiation of social labels and the borders of who was let in to their epilepsy identity.

According to Schneider and Conrad’s (1981) sociological “epilepsy typologies” (as reviewed on p. 40), participants relied heavily on social boundaries to allow themselves time to develop self-conceptualizations prior to disclosing information about their illness. The typologies emphasize that “adjusted” individuals have adapted to epilepsy as part of their identity, with coping behaviours ranging from complete secrecy, pragmatic sharing, and finally attempts to announce their illness for public education or “therapeutic telling” (Schneider & Conrad, 1981; Kilinc & Campbell, 2009). Notably, the “unadjusted” individuals are identified as those who perceive no sense of agency over their identity, as epilepsy has taken control. Rose was perhaps my most effective educator regarding the challenge that aging poses to this paradigm, not to

mention epilepsy conceptualizations and treatment as a whole. While the other participants seemed to cast themselves as adjusting to epilepsy through temporal shifts and decreases in social boundaries, Rose appears to create more social boundaries over time and seems increasingly flooded by an illness that continues to change with age. This is yet one more reminder that the models and metaphors that carry such value in one moment are constantly shifting, and that the boundaries that are prized for their perceived control may easily shift given the unpredictability of the life with epilepsy. Rose's shrinking and shaken nest helpfully illustrated the fragility of her self and her boundaries over time, however, it does not necessarily provide a specific terminology to focus on. Instead, with social boundaries presented through different and changing terminology between individuals and narratives, we may consider this to highlight the need to be aware of changes in the language being used.

9.7 "Listen to the Body": Metaphors of Physical Discipline

We have considered how the first seizure experience impacts each individual's further epilepsy conceptualizations; Grace's narrative is both constructive and unique in this sense. Grace began with and returned to a focus on dance as both a passion and a talent. Interestingly, her descriptions of dance conflict with her descriptions of seizures in two ways that perceived control play a central role: dance requires physical discipline, as well as physical trust—that is, allowing your body to freely move with the music. The seizures and medications that I considered to be her focus in her narratives were those that interfered with these physical functions. Her metaphors tended to focus on the physical self as a priority for both communication and control, regarding the loss of physical control during a seizure or her inability to control her dance moves due to side effects of her anticonvulsants. It is difficult to say whether Grace's focus on the physical was prompted by her passion for dance, prior to the occurrence of seizures, or by her later seizures that interfered with her ability to dance. Despite

the fact that each participant that I spoke with had recalled physical seizures, Grace's narrative was the only one that I observed to maintain this central focus.

As illustrated by Hannah's quote regarding seizures as "freaky," above, each participant's knowledge of epilepsy prior to diagnosis appeared to focus on the violent, physical seizures that individuals experienced. This prior understanding seemed to influence their relationships with physical symptoms and their epilepsy, albeit in different ways. For Grace, she tended to be dismissive of those seizures and symptoms that were not physically or visibly intrusive, including how symptoms were reported to her physicians and ultimately how she was treated. Further, her father's recognition of her physical seizure prompted him to disclose his history of epilepsy to his daughter, and to provide support in accessing community resources. Clark and Hannah reported minimal detail regarding their own physical seizures, yet they both provided detailed reports of visible and "scary" seizures that they had observed, and in which they seemed to frame themselves as the source of support, the saviour or the witness. Hannah, as well as Cam, both seemed to minimize their seizures, which they described as manifesting primarily as cognitive rather than physical disturbances and, when they did identify physical seizures, they described them in such a way that they were distanced from the experience. For Cam, he was asleep or simply labelled these seizures without description, for Hannah, she identified these as seizures that occurred in her body that was distanced from her self. Rose's descriptions seemed to hold a tone most similar to Grace's in that she described an active and physical self, working with tools and climbing ladders, that was unwelcomingly disrupted by seizures. Unlike Grace, Rose made few adjustments to her physical identity until her seizures were so intrusive that she had no choice. Ultimately, each individual held a strong role for the physical elements of epilepsy, whether they used it to characterize the violent seizures that the public associates with epilepsy or they used it to characterize their own struggle for physical control.

9.7.1 Physical discipline and control. Grace’s reported interactions with her dancing were for me the best illustration of the intersection of physicality and perceived control in epilepsy. As physical control became threatened, so too did her ability to communicate through her preferred method — dancing — as well as her ability to convey experiences for which she had never needed words, such as the ability to leap without her legs “scissoring” due to a seizure. Her and her father’s reported interactions, as well as their past interactions with physicians, helped give context to earlier studies in which diagnoses were often a general “epilepsy” label but which we now have learned are a group of “epilepsies” in which varied experiences of physical loss of control is a threatening hallmark that many individuals understand as an uncertain fate (Stirling, 2010; Young et al., 2002). Communicating the identities of someone living with epilepsy was illustrated to be challenging, as Grace described her physical seizures as a source of proof that validated her epilepsy experiences with peers and enabled a storied sense of control. Nonetheless, both Grace’s father and earlier epilepsy research identified these same experiences as illustrations of loss of physical and social control, in which individuals were defined by physical actions over which they had no power (Kirchglasser, 1990). Grace echoes the wisdom of Charon (2012), that individuals and practitioners alike must “listen to the body” to understand and validate the needs of the individual. For individuals with epilepsy, a battle with the body seems to be either their introduction to or their anticipated fate with epilepsy. Metaphors used to describe the body and the subjective experience of a seizure play a crucial role here for clinicians, as these can help direct attention to the individual’s experience of seizures. In moving towards trying to control seizures, or empowering individuals to perceive control over seizures and their bodies, such discussion can ensure that the individual and, in a sense, the body has been heard.

9.8 Implications

While each narrative provided rich materials with extensive use of metaphor, they cannot be considered generalizable. Nonetheless, the contrast and comparison of the five narratives provided throughout my *Analysis* chapters and within this chapter underline perceived control as a common target for metaphor use, and also highlight similarities in those metaphors used to conceptualize this desired control. With an extensive amount of epilepsy research emphasizing loss of control and a desire to regain control as prominent narrative outcomes and more recently, a focus of psychotherapy targets, the examination of language used to communicate control in epilepsy becomes increasingly more relevant. Let us now turn to some closing thoughts and conclusions regarding this study as a whole.

CHAPTER TEN

Summary, Conclusions, and Future Directions

In this final chapter, I will provide a summary of the research including a review of the study rationale, objectives, and methodological approach. Second, I will consider unique challenges that I encountered, some of which made for distinct contributions to the study and others that I see as limitations to be considered in reviewing the findings. Third, I will summarize the main findings as touched upon in the preceding chapter, highlighting those common conceptualizations that appear to capture the relationship between epilepsy and control, involving perceived loss of control and attempts to reclaim it. I will close this section with future directions for the application of these findings in public, clinical, and academic forums.

10.1 Study Rationale

I began this study with the goal of exploring how people with epilepsy use metaphor in discussing their illness experiences, so that I might understand how language may help or hinder the meaning of seizures and epilepsy in their lives. I first became aware of the prevalence of metaphor in epilepsy-related terminology that I had observed in my Master's research, with primarily biomedically-based terms such as neurons "firing" and "misfiring," and "kindling" as the initiation of such a "fire." In further exploring the history of epilepsy, I encountered diverse societal beliefs of the "sacred disease," individuals being "possessed," and the "falling sickness." What sparked my interest even more so were individuals' published narratives; these publications illustrated a blend of terminologies that the authors connected to biomedical encounters, societal beliefs as shared by family and peers, and expressions that appeared unique to individual experiences. These expressions of meaning — through stories, images, music, and dance — made it clear that those with epilepsy had plenty to communicate and I wanted to hear it all.

These encounters were the motivation behind my final research product: an analysis of five individual narratives, captured in both written and oral format, with a focus on how language was used and to what ends. I will now remind readers of the study objectives and methodological approach developed, including consideration of methodological elements that are seen as benefits to the study (e.g., written and oral narrative approaches), as well as aspects that can be seen as limitations (e.g., sample size, generalizability of results).

10.2 Study Objectives

The main purpose of the study was to inform research and health care communities regarding individual perceptions of epilepsy as conveyed through language — specifically metaphor — in order to increase an understanding of the way in which language impacts meaning of illness and self for individuals with epilepsy. The first question that guided my research was: *What metaphors do individuals use to communicate and make sense of their epilepsy experiences, and what role do these metaphors play?* Further, I questioned: *How is storytelling used by people with epilepsy to make sense of their experiences and to re-construct identities after diagnosis? How are metaphors used in the (re-) construction of these stories? Are these metaphors prevalent in existing discourses surrounding epilepsy (e.g., biomedical terminology, socio-historical beliefs) or are they more often idiosyncratic?*

I observed that the participants in my study identified their first seizure experiences as perceived losses of control, and then sought to regain or reclaim this perceived control. Frequently, metaphors were used to convey these seizures experiences and the responses that followed, such that participants seemed to use their terminology to identify, and then address, their relationships with seizures, epilepsy, and control. The results seemed to point to both positive and negative ways that metaphors may be involved in the meaning-making process related to epilepsy and the associated perceived loss of control. By reviewing both the target

domains of these metaphors (e.g., the seizure experience, social experience of the epilepsy label) and the metaphors themselves (e.g., a gap in time, a witness, shaking the nest), I have considered how awareness of language is one way in which we may support individuals making sense of their seizures and an epilepsy diagnosis. These meanings reflect those that were significant for my participants specifically, and thus cannot be generalized to the epilepsy population as a whole. However, the research highlights the importance of attending to the role that language plays in individuals' experiences. This study aims to serve a larger discourse of illness experiences as a whole, but specifically with epilepsy, which represents the most common neurological condition diagnosed and treated in primary practice (Fisher et al., 2005). There exists not only a serious history but also ongoing biomedical and societal dialogues in an attempt to “capture” and “control” the illness.

10.3 Revisiting the Methodological Approach

Here I will briefly revisit my methodology as a reminder of the analytic approach used so as to acknowledge unique aspects of the approach, as well as to consider limitations of the methodology that must be recognized as they impact the utility and purpose of the study findings.

10.3.1 Methodology: Metaphor and narrative analysis. My study was initially prompted by narrative research on cancer patients, in which it was identified that individuals, in order to script their narrative and make sense of their illness experience, used specific and often idiosyncratic metaphors (Teucher, 2003; Teucher et al., 2010). I became further interested in narratives of individuals with epilepsy specifically in following the research history on the illness, in which biomedical discourse has directed much of the quantitative research (e.g., Fisher et al., 2005, 2014), while qualitative research has highlighted the diverse experiences of individuals who have experienced this illness (e.g., Faircloth, 1998a; Nijhof, 1998). A collaborative approach between neurologists and linguists (Schwabe et al., 2007, 2008; Plug et

al., 2009) was successful in identifying, using quantitative and qualitative approaches, the numerous metaphors used by individuals to describe seizures in an open-ended interview format. My study was largely influenced by these findings, in an attempt to build on the seizure-specific language used and to explore more elaborate epilepsy-specific metaphors and narratives that might surface when individuals were asked to provide their stories with minimal prompting. Here, I approached metaphor in its multiple uses: as individual terminologies used to convey an experience, as narrative linkages that create a narrative whole, and at other times as the use of overarching concepts that held the narratives together (Bruner, 1990; Denzin & Lincoln, 2000; Kirmayer, 2004). The use of metaphor analysis added an element that has previously been researched for its diagnostic purposes but can also serve a crucial role in: 1) understanding the process of meaning-making in the patient (Kirmayer, 1992, 2000); 2) educating health care practitioners regarding how communication strategies impact mutual understanding of illness experiences and treatments (Conrad, 1985, 1992; Charon, 2012); and 3) encouraging language awareness in the use of therapeutic approaches meant to address psychosocial needs (Brosh, 2011; Kirmayer, 2004; Snape, 2015).

In preparation for my study, I reviewed published narratives and considered the possible differences that might exist in these written narratives, which individuals may prepare through independent reflection, as opposed to oral narratives that are provided in conversational format. This led me to request that participants provide me with a written narrative of their experience, as I was interested to observe what differences might present in the different narrative formats.

10.3.2 Methodology: Written narratives. A novel approach that I took was to collect written narratives from participants prior to collecting oral narratives. This provided them with an opportunity to communicate what they might have seen as most important, as well as to communicate it in whichever way they felt it most appropriate. It provided me with an

opportunity to review their written stories and note initial observations, as well as learn their “vocabulary” in the sense that I made note of the terminology they used and attempted to respect this terminology throughout the oral interview process. Certainly, there were differences between the narrative formats, and this highlighted the strengths and weaknesses of either approach independently. In the autobiographies that I had read in advance, I noted a “smooth” — and likely edited — approach in which individuals presented their experience in a traditional “storied” format in which they often identified an event with which their epilepsy narrative began, followed by a chronological trajectory of events (Frank, 1995). This provided me with some insight as to what I might encounter with my participants and, indeed, their written narratives often started with a pivotal date or first event, often their first seizure or initial diagnosis as had been noted by other researchers (Snape, 2015; Velissaris et al., 2012). There was nonetheless heterogeneity in the presentation of written narratives.

As discussed throughout the *Analysis* chapters, some participants focused more heavily on past experiences with epilepsy, often the early stages of discovery and diagnosis, while others focused on current day, reflecting on how epilepsy had impacted their lives overall. Also addressed in the individual *Analysis* chapters is the heterogeneity in the structure of the written narratives. Rose provided point-form lists of slang and epilepsy-related terminology to communicate her experience, reflecting and reinforcing her opening statement, “*I am not comfortable doing this.*” In contrast, Cam provided a reflection on the emotional and lifestyle transitions that took place after the capitalized “Epilepsy” became a part of his life. Hannah, Grace, and Clark took what could be considered more traditional storytelling approaches to their written narratives, describing in a conversational style the chronological trajectories that began with first seizures and ended with their current medical status (Charon, 2006). As discussed, all participants provided final thoughts on epilepsy as their end point, some consisting of advice for

others with epilepsy, others apologizing for providing narratives of which they themselves questioned the value.

I consider it a privilege that I was invited to witness very personal reflections, some of which were not repeated in the oral narratives. I interpreted this to be at least in part a consequence of the fact that with me sitting across from them, they might be more aware that there was audience and perhaps more guarded in what they chose to discuss. With other participants, however, the opposite was true and I again had the privilege of hearing very personal reflections that were not shared in their written narratives. The oral narratives were conducted were done using an open-ended interview structure guided by the participants but also based on prompts from a general interview guideline that was adapted following the reading of each individual's written narrative (see Interview Guide: Appendix F). The oral narratives provided an opportunity to gain elaboration on terms of interest that were used in the written narratives. In reviewing the oral narrative transcripts and comparing them to the written narratives collected, the oral narratives did not appear as edited as those that had been written, based on factors such as the style of communication (i.e., more colloquial in oral narratives as opposed to more formal in written narratives) and the sometimes circular or less direct type of communication (e.g., repetition, pauses in speech). Ultimately, the use of written and oral narratives, as well as additional resources that many participants offered in our meetings (e.g., magazine articles, book titles and reflections, YouTube videos, etc.), enabled me to observe their language use in different mediums. Having written their narratives prior to our oral narrative meetings, participants seemed to arrive with reflections that they were eager to continue elaborating on. This also provided me with the opportunity to gain insight into their possible vocabulary use and to anticipate topics that they might identify as central, or avoid intentionally or inadvertently, all of which provided me with more information to consider in my analysis.

10.3.3 Methodology: Epistemological assumptions. This collection of narratives presents individuals' and my own perceptions of epilepsy experiences, narratives that have been constructed using the linguistic resources encountered in their interactions, including their interactions with me (Gergen, 2015). This addresses my interpretivist stance in collecting and reconstructing narratives based on the meaning made of these narratives by myself and by the participants at the time that we spoke (Willis, 2007). By no means am I suggesting that the narratives analyzed and the conclusions drawn are based on a singular reality, but rather reflect and contribute to a necessary dialogue and a contextualized understanding of experiences of epilepsy (Crotty, 1998; Gergen, 2015). Hopefully, these narratives provide distinct perspectives and insights into the language that best serves this population. This might help direct future research efforts whether from the biomedical, psychosocial, and/or linguistic fields, for example, in appreciating the unique experiences of each individual attempting to make sense of her or his experiences.

10.4 Limitations

I must acknowledge my own role in co-constructing the narratives presented, as participants shared their experiences with myself as a listener, an asker-of-questions, and ultimately the one who identified what aspects I perceived as meaningful for the purpose of analysis and re-construction of these narratives (Gergen, 2015). Again, in line with a social constructionist perspective, I acknowledge that other individuals and listeners might find equally valid but different interpretations of the narratives (Crotty, 1998). In line with Thorne's (2008) criterion of interpretive authority, I have made every effort to be transparent in my reflections on why and how I have prioritized specific findings, as well as through the process of contextualizing, reviewing, and re-visiting the various narratives collected to consider how my

own perspectives and insights might shift as a consequence of the iterative process of writing and re-analysing my data.

10.4.1 Sample size. An additional limitation to this study, and one that was anticipated based on my methodological approach, was the small sample size. My goal was to engage individuals with diverse experiences in order to observe how different language use might present differently across narrators with demographic differences, such as gender, marital status, seizure types, and treatment types. I spoke to 10 individuals regarding participation in the study, six of whom ultimately felt comfortable providing written and oral narratives. One of the six participants did not meet the inclusion criteria, as he had not had a seizure or received treatment for seizures in approximately 50 years. Nonetheless, he was still invited to contribute his narratives from the perspective of a person with epilepsy, as well as a father to one of the other participants. Ultimately, five narratives were used as primary material for the chapters written, with some perspectives from the sixth participant included in his daughter's narrative in Chapter 8. In the end, the five participants constitute a diverse demographic presentation: two men and three women who presented with different marital status (two married, two divorced, one single), three were parents, and different epilepsy presentations (e.g., seizure type(s), age of seizure onset, duration of seizures since onset, treatment type(s), and degree of seizure control). Nonetheless, my sampling was limited by the number of individuals who responded to an interview request (self-selection) and half of the respondents came from the local epilepsy organization, suggesting individuals who may have had more exposure to resources and been more familiar with talking about their experiences.

While the results cannot be considered statistically generalizable given the limited number of participants and study design, the narratives present rich epilepsy conceptualizations and metaphors that can contribute to analogical generalizability (Sandelowski & Leeman, 2012;

Smaling, 2003). Analogical generalizability is based on analogical reasoning in which the results from one or a few cases may be considered to support or falsify an established case-based theory. In the case of the current study, one of many such considerations would be the replication of the finding that “control” is a prevalent theme in individual epilepsy narratives, albeit represented through different forms of language representing, at times, different types of control (Nijhof, 1998; Faircloth, 1998a). Smaling (2003) emphasizes that the “thick description” provided in the research of individual cases, as was done in this study, facilitates “transferability” or “communicative generalization,” a type of analogical generalization, in which future readers and researchers may consider the how the present results may be relevant to their research while still acknowledging the context-specific set of findings. Transferability has continued to play an increasingly acknowledged role for researchers interested in practice-oriented and applied health research, and presents a promising way in which the current research can be considered for future research and practice (Sandelowski & Leeman, 2012).

10.5 Summary of Findings

Biomedically, epilepsy is diagnosed based on the occurrence of seizures and the underlying neurophysiology responsible for the seizures (Blume et al., 2001). As illustrated by the ever-evolving definitions of seizures and epilepsies, researchers and clinicians are increasingly aware of the importance of language in accurately capturing and conveying the illness. In carrying out this research, I wanted to shift focus from how language may primarily be used for epilepsy diagnosis and treatment in the biomedical domain, to how language use impacts interactions, interpretations, and subjective experiences for those living with epilepsy. A primary goal was to further understand and inform the way that language, including any literal or metaphorical communication, can impact the multifaceted nature of the condition. Each individual demonstrated a powerful role for language in her or his narratives that helped to

achieve the goal of understanding both what is felt necessary to communicate, as well as how this is achieved.

Hannah's framing of the witness role illustrated the ways in which this concept can be perceived as both empowering or disempowering, depending on the participants' abilities to move between these roles, and drew my attention to the way in which medical terminology can significantly impact individuals' perception of their illness and themselves. Clark illustrated for me how some very traditional concepts surrounding disease and illness provide linguistic resources that may play key roles in the individuals' ongoing attempt to understand and perceive control in what is often a lifelong relationship with epilepsy. Cam's focus on labels and time at first appeared to be a very straightforward depiction of epilepsy; however, his choices surrounding which labels were claimed, re-defined, denied, and removed after surgery added another new element to be considered in epilepsy research. Rose illustrated for me the role that social boundaries play in enabling individuals to continuously negotiate a safe space in which they and their illness may exist. Further, her perspectives regarding the impact of aging on these boundaries helped me to consider new developments to integrate in an area of sociological epilepsy identities that were seemingly developed as more static labels. Finally, Grace highlighted how the physically violent seizures often associated with epilepsy may represent a fraction of the physical and emotional challenges associated with this illness and its treatment, including reliance on one's body for communication when language does not suffice.

Overall, metaphors used in reference to seizures appear to be largely consistent throughout each individual's narrative, beginning with the depiction of the first seizure. While the early experiences that participants tied to these first seizures could suggest that the first seizure plays a significant role in dictating or determining the conceptualization of seizures and epilepsy over time, we must consider that these stories have been told retrospectively and thus a

more scripted and coherent story may have evolved out of originally inconsistent or isolated experiences. While each participant highlighted for me some unique metaphors that I felt useful in my search for the role of metaphor, it must be acknowledged that patterns are mutable. Thus, we cannot assume that one category of metaphor will always apply to one participant, so much as appreciate the evolution of the individual and her or his illness, and a tendency to shape-shift over time. This further suggests that those striving to support the epilepsy community must not only be open to changes, but should expect them. These changes may result from diverse sources including social dynamics, medical interactions and treatments (e.g., drugs, surgery), changes in seizure presentation, and many more possibilities. The same can be said of individuals and their communication strategies; that is, metaphors are useful tools in patients' communication and search for perceived control, but many of these metaphors may change over time.

Epilepsy's long history of cultural representations has led many researchers, psychologists and linguists among them, to highlight the role that both biomedical and societal conceptualizations have on the individuals' constructions of their illness narratives. Stirling (2010) has emphasized the complexity of these multiple linguistic resources stating that there exist *"trade routes between culture and medicine and an unacknowledged traffic between systems of representation that accrete to produce the complex and layered meanings adhering to epilepsy and 'the epileptic'"* (pp.xiii). While I have repeatedly visited the impact of these "systems of representation" as resources with which individuals construct their epilepsy experiences, it is without question the individuals themselves who negotiate and define how their ever-evolving relationship with epilepsy can and will impact their identities. From interactions with my participants, my understanding narrowed to focus on the linguistic resources used to convey perceived control. The emphasis in using metaphor to convey perceived control highlights both the importance of such metaphors in enabling individuals to script their

narratives, as well as the value that language carries and can offer to psychotherapies already directed at addressing the increasing need for perceived control in epilepsy (e.g., Michaelis et al., 2012; Tang et al., 2014; Wilson et al., 2005). Many metaphors that were consistent with perceived control were also in keeping with the illness-as-normality narrative, and highlight the way in which those with epilepsy attempt to control their epilepsy largely by trying to find meaning in the life that is lived around the illness, rather than within it (Frank, 2010; Velissaris et al., 2007).

10.6 Future Directions

As noted, a primary finding was that all narratives contained conceptualizations of control and given this emphasis my findings became focused on conceptualizations of control in epilepsy. These included, for example, loss of physical control and/or cognitive control during the first seizure experience, renegotiations of physical control, renegotiations of identity control in relation to diagnostic labels and social relationships, and medical relationships. The comparison of the narratives carried out in Chapter 9 demonstrates how perceived control is a common target for metaphor use, highlighting common targets of the epilepsy experience over which participants seek to gain perceived control (e.g., seizure experience, social boundaries, physical control), as well as conceptualizations used to convey this perceived control that seem to originate from common sources (e.g., witnesses, mechanical metaphors), as well as more unique language use (e.g., nests, superheroes). I will now close by briefly considering possible applications for these primary findings of language use in clinical and everyday interactions contexts.

Epilepsy poses unique challenges as an illness in which in/visibility is a transient reality. Perhaps what reinforced this realization was the difficulty I had in encouraging individuals to share their stories, even anonymously. I was reminded of the transience of this invisibility when,

over the course of my study, participants who had shared their stories decided that they no longer chose to discuss their epilepsy or to engage with the epilepsy community. These interactions, from written and oral narratives to ongoing encounters, repeatedly highlighted the fragility and vulnerability of identities that rested on unpredictable bodies. While I had spoken to potential participants informally who had decided they were not comfortable sharing their epilepsy experiences, I was surprised when I discovered that even individuals who had seemingly chosen to live with epilepsy as a central aspect of their identity had returned to a more invisible stance. Captain was perhaps the most vocal regarding this reality, explaining that he wished his peers would be more supportive and exclaiming, *“I don’t want to be Captain Epilepsy all the time, but if they need somebody to step out of the phone booth, I’ll be there.”* The safety of such an alternate identity appeared to provide participants, such as Cam’s “Consistent Cam” and Hannah’s “Healer” with the choice of protecting their identity when they felt they needed or wanted to reclaim control. Epilepsy then exists as a challenging illness to support psychosocially as individuals may transiently benefit from peer supports and community groups, but may also be reluctant to identify as living with epilepsy. Importantly, this variability exists between and within individuals, for example, as Rose described how aging with epilepsy had led her to live within her “safe nest” where there was no longer room for her community group. The psychological implications of this transient invisibility and potential isolation are very real, and should be considered in the increased efforts to offer psychological support to individuals with epilepsy (Brosh, 2011; Tang et al., 2014).

10.6.1 For clinicians. In descriptions of narrative medicine, Charon (2006) emphasizes the importance of bearing witness to patient suffering, in part to help them regain a sense of power or control:

Our narrative efforts toward ethicality and intersubjectivity enable us to not just feel on the patients' behalf but to commit acts of particularized and efficacious recognition that leads beyond empathy to the chance to restore power or control to those who have suffered (p. 181).

While her statement is directed to clinicians in general, its relevance to the practice of epilepsy treatment specifically is valuable given the focus of this illness as one in which the search for perceived control is an ongoing challenge. Not only should clinicians strive to gain an awareness of the experiences that an individual with epilepsy may be communicating; they should be equally mindful of the language with which they converse regarding epilepsy experiences. As has been highlighted by researchers and illustrated in the preceding narrative analyses, a perceived mastery of medical discourse brings with it the perception of control (Conrad & Barker, 2010). While individuals may be striving to gain understanding and control of their experiences, the use of terminology without clear explanation or, conversely, the assumption of a verbal report without adequate clarification can lead to significant misunderstandings and inaccurate conceptualizations. Grace's perception of seizures that were out of her control and "electric" in nature following a neurologist's description of neuronal electricity is but one example of the implications of unclear communication. Given that many individuals with epilepsy are engaged in a lifelong struggle for perceived control, it is even more pertinent to empower such individuals by attending to their communication attempts and providing them with accurate resources for communication.

10.6.2 For public awareness. An accurate understanding of epilepsy is key for individuals living with the illness, although this education could be beneficial more broadly. All participants identified previous awareness of epilepsy, conceptualized as violent and scary physical seizures. It was only through personal experience, as well as engagement with medical

resources and community supports, that individuals appeared to gain awareness of the diversity of epilepsy presentations. The ILAE continues to modify its terminology in attempts to address the multifaceted nature of epilepsy (e.g., physical, cognitive, psychosocial consequences of the illness and label), as well as attempts to address the need for accuracy in seizure diagnosis and comprehensiveness in diagnosing a “family of illnesses” — the epilepsies — with incredibly diverse symptom presentations, both visible and non-visible.

10.6.3 For future research. Reuber, Plug, and colleagues (e.g., Monzoni & Reuber, 2009; Plug, Sharrack & Reuber, 2009, 2011; Schwabe et al., 2007, etc.) have introduced a novel and diagnostically-relevant approach to the diagnosis of seizures, by encouraging neurologists to listen to patient descriptions rather than performing a traditional medical interview, and by identifying seizure-specific metaphors that may be likely to guide accurate diagnosis of epileptic as opposed to non-epileptic seizures. The current study sought to consider epilepsy conceptualizations and metaphors, not for the purpose of diagnosis but to further the understanding of treatment targets and communication approaches. With control as a longstanding focus in epilepsy research and perceived control as more recent target in epilepsy psychotherapies (e.g., Michaelis et al., 2012; Tang et al., 2014; Velissaris et al., 2012), the current study built on these fields with metaphors used to conceptualize and convey experiences of control in epilepsy. While this study focused on only a few narratives in identifying these patterns in language use, the findings are encouraging and do suggest future possibilities for utilizing participant conceptualizations of epilepsy experiences and control in providing more appropriate and more targeted therapies. By gaining a greater understanding of the role that metaphor plays in individuals’ experiences of epilepsy and associated identity re-construction, researchers can continue to provide improved psychosocial support to this population.

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Appendix A: Published Narratives

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*indicates story involving surgical treatment & “control of seizures”; restitution narratives

**indicates collection of narratives, some of which involve stories of surgical treatment

Appendix B: Seizure Classification and Descriptions

Focal or Partial: The site of origin of the seizure (i.e., seizure focus) is a localized or discrete area in one hemisphere of the brain. The two most common partial seizure types are simple partial and complex partial. Seizure activity may begin as a partial seizure and become secondarily generalized.

Aura: Sensory experience (e.g., auditory, autonomic, psychic, sensory, or visual) that some people experience before a seizure begins. Sometimes referred to as a “warning.”

Simple partial: Brief (lasting seconds to minutes), consciousness is retained, and may consist of a subjective sensory experience (e.g., auditory, autonomic, psychic, sensory, or visual) or a motor manifestation (clonic, myoclonic, or tonic).

Complex partial: Brief loss of consciousness (lasting seconds to several minutes). While unconscious, the patient may appear to stare or display facial expressions (e.g., fear, confusion, bewilderment), and may display automatisms such as: chewing, salivation, repetitive hand movements, laughing, crying, wandering, running, or repeating short phrases. Associated with other seizure phenomena including subjective sensory experiences (e.g., auditory, autonomic, psychic, sensory, or visual).

Generalized: Seizure activity occurs simultaneously in large areas of the brain, often in both hemispheres. These seizures can be convulsive or non-convulsive. These seizures may involve generalization at seizure onset, or may be secondarily generalized, beginning as a partial (focal) seizure. The two most common types include absence and tonic-clonic.

Absence: Referred to as “petit mal” in the past. Abrupt loss of awareness, with staring, sometimes with rapid blinking, eyelid flickering or subtle loss of tone in eyelids, face, or limbs. Usually lasts about 10 seconds or less, can occur many times daily, and can often be mistaken for daydreaming.

Clonic: Rhythmic, symmetrical shaking of limbs, face and neck that can be due to a focal or generalized seizure.

Myoclonic: Rhythmic muscle jerks that can affect part of the body or the whole body. Appears as sudden, irregular, jolt-like movement of the head, neck, trunk, or limbs in any combination. These seizures involve sudden muscle contractions that are so brief that they may go unnoticed, or may be mistaken for a tic.

Tonic: Stiffness and extension of the limbs and trunk. When generalized involves loss of consciousness, often with a fall.

Tonic-clonic: Previously referred to as “grand mal” or “convulsions,” may be due to a focal or generalized seizure. A seizure involving two phases: a tonic phase, consisting of increased muscle tone (rigidity), followed by a clonic phase, consisting of jerking of the extremities. Often starts with a cry or yell, and is accompanied by autonomic symptoms for example: increased blood pressure and heart rate, increased bladder pressure and incontinence, sweating, increased salivation, increased bronchial secretion, and possible apnea. There may be lateral tongue biting. Often followed by post-ictal phase of confusion, sometimes with aggression or tiredness.

Juvenile myoclonic epilepsy: A condition that begins in childhood or adolescence and lasts into adulthood. The most common seizure type experienced is myoclonic jerks, but people with this

condition type may also experience generalized tonic-clonic (grand mal) seizures. Seizures can happen any time but occur most commonly in the morning.

Appendix C: Interview Guide

Introduction

Participants will be provided with an introduction to the study and will review the consent form. At this time they will also be provided the opportunity to choose a pseudonym if they would like their identity to remain confidential. Participants will also be informed of the types of questions that will be asked and that there are no “right” answers to any questions. Participants will be reminded of their right to refuse to answer questions and/or withdraw from the study at any time.

Background

The interview/conversation will begin by asking participants to introduce themselves and general information about their background:

Can you tell me about yourself? (Prompts: Employment, marital status, children)

Questions for Participants

The interview will be as unstructured as possible, allowing the participant to guide the process.

The following questions and prompts will be provided only as needed:

- 1) Can you tell me about your experience with epilepsy?
How do you make sense of epilepsy?
How do you give meaning to your experiences?
- 2) Can you tell me about your diagnosis and treatment?
How did you make sense of your diagnosis?
How did/do you make sense of your treatment?
- 3) How has having epilepsy affected your life?
What aspects of your life have been most affected?
How has epilepsy impacted your relationships (e.g., family, friends, work)
- 4) Participants will be asked to reflect upon the writing process (if it has already been completed) and share any insights they encountered while writing.
What did you feel was most important to include in your writing?
What did you find particularly interesting or difficult to write about?
Did anything surprise you about your writing?
- 5) Are there any metaphors or images that you use, either in conversation or in your writing, to describe your experiences with epilepsy?
(For example, what would you say “Epilepsy is like...”?)

Are there metaphors that you have heard from others (e.g., physician, family, friends, etc.)?

How do these metaphors (personal or public) impact how you make sense of your experiences with epilepsy?

Appendix D: Advertisement

Making Sense of Life with Epilepsy: A Study of Individual Narratives

We Would Like to Hear Your Story!

An Invitation to Participate in Research about Experiences with Epilepsy

We are seeking:

Adults who have been diagnosed with epilepsy, and who would like to take part in a research study in which you share your experiences in writing and speaking.

Why?

To learn more about how epilepsy affects the lives of those living with it,
and to consider how we talk about this illness.

We hope that, by gaining a greater awareness of how epilepsy is discussed and understood, we can improve public awareness and psychosocial support for those diagnosed and living with epilepsy.

If you are interested in learning more about this study...

Please contact **Devon Andersen** by phone: (306) 966-6944 or email: devon.andersen@usask.ca for more details. You are under no obligation to participate if you call or email. This research is funded by the Canadian Institute of Health Research (CIHR) and the Saskatchewan Health Research Foundation (SHRF).

Appendix E: Letter of Invitation to Join Research Project

Life with Epilepsy: Sharing Your Story

We would like to talk to you about your experience in living with epilepsy. Because different people make sense of their epilepsy in different ways, this research project invites you to share with us how you personally have made sense of your experiences with epilepsy. Our goal is to call attention to the way in which different people speak about and make sense of epilepsy, to highlight the ways in which their lives are affected by this condition and to improve the quality of care provided to individuals with epilepsy.

We are looking for adults who have been diagnosed with epilepsy to participate in this study. Participants must also meet the following criteria:

- Are 18 years of age or older
- Have been diagnosed with epilepsy at least 3 months ago
- Are able to write and converse in English
- Are willing to participate in a writing activity and/or an audio-recorded interview
- Are willing to share personal experiences of epilepsy and epilepsy treatment

*Please be aware that your identity will be kept confidential

We would like to learn how epilepsy and its treatment might affect our sense of self, health and illness, social supports, and our independence. Sometimes, it is not easy to find words to describe one's experience with epilepsy. We are interested in the words and images that you may use, those that you may have heard, and those that you have found useful as you try to make sense of epilepsy and its treatment.

The study will use written pieces and interviews as methods for exploring experiences with epilepsy. This study will involve two parts. In Part 1, you will be invited to write an account of your experiences with epilepsy. You can share whatever experiences you find most important or most interesting. In general, we are interested in learning how you think about your illness, from diagnosis to treatment, and its impact on your everyday life. In Part 2, you will be asked to participate in interviews regarding your experiences about life with epilepsy. If the Part 1 written component has already been completed, we may discuss what has been written. The meeting will be about 60 to 90 minutes and will be held in the Qualitative Research Centre on the University of Saskatchewan campus. We will provide you with transportation and refreshments.

Your identity and the information you share will be kept strictly confidential. You will have the option of using a pseudonym (i.e., being assigned a name) and you will be given an identity code for the purpose of linking your written material and your interview transcript. All data will be accessible only to the researcher and research associates. All data will be kept in locked storage, and all interview recordings will be destroyed beyond recovery after transcripts have been completed. Participants will be given the opportunity to review transcripts of interviews prior to the completion of the study. Your participation is entirely voluntary. If you have any concerns, you have the choice to not answer any questions that you might feel uncomfortable about, or you

may withdraw from the study at any time and/or you may withdraw any of the information at any time, without any repercussions. Your choice to participate or not will not be communicated to your physicians and will in no way affect your medical care. A final report will be available upon request, once the study has been completed.

There are no intended benefits or risks associated with this study. While sharing your experiences with epilepsy may evoke an emotional response, participants may find that sharing their stories is beneficial. Should you find that the process of sharing your experiences upsets you, counselling services will be made available to you at Epilepsy Saskatoon (306) 665-1939 or Family Service Saskatoon (306) 244-0127. It is hoped that this study will help others to better understand the ways in which epilepsy impacts those living with it.

If you have any questions about this study, please contact **Devon Andersen** by phone: (306) 966-6944 or email: devon.andersen@usask.ca for more details. You are under no obligation to participate if you call or email. If you wish to participate, please sign the attached Consent Form and mail it to us using the addressed and stamped envelope, and keep the second copy of the Consent Form for yourself. We will then make contact with you and set up a meeting time that is convenient for you.

We thank you for your time and look forward to hearing from you!

Sincerely,

Devon Andersen, M.A.
Graduate Student, Department of Psychology
College of Arts and Science
University of Saskatchewan
Telephone: (306) 966-6944
Email: devon.andersen@usask.ca

Dr. Ulrich Teucher, Ph.D.
Assistant Professor, Department of Psychology
College of Arts and Science
University of Saskatchewan
Telephone: (306) 966-2529
Email: ulrich.teucher@usask.ca

Appendix F: Consent Form



CONSENT FORM

*You are invited to participate in a research study entitled **Making Sense of Life with Epilepsy: A Study of Individual Narratives**. Please read this form carefully and feel free to ask any questions you might have about the study.*

Student Researcher: Devon Andersen, Department of Psychology, University of Saskatchewan, 966-6944, devon.andersen@usask.ca

Research Supervisor: Dr. Ulrich Teucher, Department of Psychology, University of Saskatchewan, 966-2529, ulrich.teucher@usask.ca

Purpose and Procedure: This research aims to understand the language that individuals with epilepsy use to describe their epilepsy-related experiences. The research will contribute to the completion of a doctoral dissertation. Participants will be invited to write about their epilepsy-related experiences and to return their writing to the researcher. This writing process can take place at the participant's chosen location and can be submitted in any format (i.e., hand-written notes, journal, computer typed, etc.). Participants will generally be asked to submit their writing by June 15, 2011. Participants may be asked to participate in an optional follow-up interview to discuss their writing. This interview would take place in the Qualitative Research Centre's Interview Room on campus and would last approximately one to two hours.

Potential Benefits: By taking part in this study you will help us to better understand how some individuals with epilepsy use language to make sense of their experiences. We hope that our findings will contribute to an increased awareness of this language use in the health care community.

Potential Risks: There are no known health risks associated with participation in this study. Some individuals may find the process of writing or speaking about their illness experiences upsetting. In this circumstance, individuals will be invited to withdraw their participation and/or will be provided with referrals for counselling [Epilepsy Saskatoon (306) 665-1939 or Family Service Saskatoon (306) 244-0127] should they feel that additional support is needed. At the end of the study you will be given a sheet that further explains the nature of the study and you will be given a chance to ask any further questions that you might have.

Storage of Data: All data (e.g., your writing, interview notes and transcripts) will be stored separately from this consent form. Both the data and consent forms will be stored securely in Dr. Teucher's office at the University of Saskatchewan for at least five years after completion of the study. After that time, everything will be destroyed beyond recovery.

Confidentiality: Your data will be kept completely confidential. We will not be putting your name or any personal identifying information anywhere in the write up of this research. If direct quotes are used, any identifying information will be altered and a pseudonym will be used so that your identity is not recognizable.

Right to Withdraw: You may choose not to answer individual questions or talk about certain topics that you might feel uncomfortable about. You may withdraw from the study for any reason without penalty of any sort. Withdrawal of personal data may occur anytime before August 31, 2011. Upon withdrawal, any data that you have contributed will be destroyed beyond recovery and will not be included in the research. After August 31, 2011, it may no longer be possible to withdraw your material, as analysis will have commenced.

Questions: If you have any questions concerning the study, please feel free to ask at any point. You are also free to contact the researchers at the numbers provided above if you have questions at a later time. The proposed research was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Ethics Board on February XX, 2011. Any questions regarding your rights as a participant may be addressed to the Behavioural Research Ethics Board through the Office of Research Services (966-2084). Out of town participants may call collect. If you would like to obtain a summary of the final report, please indicate this when we meet, or contact me at (306) 966-6944 or devon.andersen@usask.ca.

Consent to Participate: I have read and understand the description of the research study provided above. I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw my consent to participate at any time and at that time, all information provided by me will be destroyed beyond recovery. A copy of this consent form has been given to me for my records.

Signature of Participant

Date

Signature of Researcher

Date

Identity Code: Our study has two parts (written and interview) and we would like to put these together. We ask that you make up a personal identity code (any 3 numbers or letters). In this way your confidentiality will be maintained.

Personal Identity Code: [][][]

Appendix G: Parallel Charting of Biomedical Summaries

Hannah: At the time that Hannah's narratives were collected, she was a 47-year old woman who had experienced myoclonic jerks and tonic clonic seizures beginning at age 15. She reported that she had stopped taking anticonvulsants in her mid-20s though she did experience occasional seizures during this time. She reported having managed her seizures through alternative health therapies (primarily Reiki and massage therapy) since her mid-20s with high success. She noted that she had experienced a tonic clonic seizure following the birth of her first child, at which point she began taking anticonvulsants. She expressed successful seizure control through lifestyle management, ongoing alternative therapies and anticonvulsants. She was a married mother of two young children.

Clark: At the time that Captain's narratives were collected, he was a 57-year old man who had experienced complex partial seizures, initially diagnosed as "anxiety attacks" at age 25. He experienced a tonic clonic seizure that was non-responsive to anticonvulsants, and continued treatment for anxiety until being diagnosed with epilepsy at age 29. He underwent surgery to address his medically refractory seizures at age 36. Shortly thereafter, he was put on Epival to address nocturnal tonic clonic seizures. At the time of our interview, Captain had been seizure-free for 10 years, reporting rare simple partial seizures (a few per year). Captain is a father of 3 who was married at the time of his diagnosis. He has since divorced and moved away from his family. He reported longstanding depression beginning in his teenage years.

Rose: Rose began experiencing generalized tonic clonic seizures at age 20. She experienced these seizures without any warning; that is, she had no conscious anticipatory feelings or physical indications that these seizures were about to occur. Her seizures were well controlled with medication for about 20 years, but she had to frequently switch medications or

use multiple medications to achieve full seizure control. Approximately 15 years ago, Rose began to experience increased frequency and severity in the nature of her seizures, including clusters of up to 5 seizures a day. She was assessed on an Epilepsy Monitoring Unit and was deemed not to be an appropriate surgical candidate. She had to go on long-term disability due to her poor seizure control at this time. She also reported ongoing depression. Her seizure occurrence and medication levels continue to be monitored by her GP and neurologist.

Cam: At the time that Cam's narratives were collected, he was a 45-year old man who had experienced complex partial seizures diagnosed at age 26. He underwent surgery to address his medically refractory seizures at age 38. After his surgery, he experienced nocturnal tonic clonic seizures that were identified as potentially psychogenic nonepileptic seizures at age 42. He was a single man who was living independently. We had met previously to arrange the written narrative and interview, though we had not spoken of his epilepsy apart from his interest in the study.

Grace: Grace began experiencing simple partial seizures at age 17. She began to experience myoclonic jerks shortly thereafter. These ranged from small "twitches" and progressed to larger movement of the limbs shortly thereafter. She noted that lack of sleep and alcohol consumption had a tendency to lead to greater seizure activity. She experienced her first tonic clonic seizure at age 17, and was diagnosed with "seizures" and began taking medication for her grand mal seizures at this point. She experienced minimal control with the treatment of three different anticonvulsant medications, though these appeared to aggravate her seizures. She was diagnosed with juvenile myoclonic epilepsy at age 19, once a neurologist established that she was also experiencing simple partial seizures and myoclonic jerks. She is currently being followed by her GP and has been seizure free (on valproic acid) for approximately 20 years.